

**COALITION MEMBERS**

American Academy of Hospice  
and Palliative Medicine  
(AAHPM)

Association of  
Professional Chaplains  
(APC)

Center to Advance  
Palliative Care  
(CAPC)

HealthCare  
Chaplaincy Network™  
(HCCN)

Hospice and Palliative  
Nurses Association  
(HPNA)

National Association for Home  
Care & Hospice  
(NAHC)

National Hospice and  
Palliative Care Organization  
(NHPCO)

National Palliative  
Care Research Center  
(NPCRC)

Palliative Care Quality  
Collaborative  
(PCQC)

Physician Assistants in Hospice  
and Palliative Medicine  
(PAHPM)

Social Work Hospice &  
Palliative Care Network  
(SWHPN)

Society of Pain & Palliative  
Care Pharmacists  
(SPPCP)

Supportive Care Coalition  
(SCC)

The Honorable Chuck Schumer  
Majority Leader  
United States Senate  
Washington, DC 20510

The Honorable Mitch McConnell  
Minority Leader  
United States Senate  
Washington, DC 20510

The Honorable Nancy Pelosi  
Speaker of the House  
United States House of Representatives  
Washington, DC 20515

The Honorable Kevin McCarthy  
Minority Leader  
United States House of Representatives  
Washington, DC 20515

February 10, 2021

**Re: Recommendations for the 117<sup>th</sup> Congress and the Biden Administration**

Dear Speaker Pelosi and Leaders McConnell, McCarthy, and Schumer:

The thirteen organizations that form the [National Coalition for Hospice and Palliative Care](#) congratulate the newly elected Members of the 117<sup>th</sup> Congress and the new Biden Administration. We look forward to working with both Congress and the Administration on improving the care of people with serious illness.

We recognize our nation is in the most serious and deadly public health crisis of our generation, which has already claimed the lives of more than 450,000 Americans. The impact of this pandemic is widespread, impacting urban, rural and suburban communities across every state and territory, and disproportionately impacting Black, Latino, and American Indian/Alaskan Native communities. We thank you for the considerable, multiple, bipartisan actions already taken to address the pandemic. The policy recommendations that follow focus on COVID-19, as well as other key drivers of quality of care and quality of life for patients living with serious illness and their families/caregivers.

***Our Coalition***

The goal of our Coalition is to ensure that all patients, families and caregivers who need it will have equitable access to quality hospice and palliative care.

Palliative care is an interdisciplinary model of care focused on relief of the symptoms and stresses of serious illness. Its goal is to relieve suffering and provide the best possible quality of life for patients and their families. By its very nature, palliative care is patient-centered care — translating patient goals to appropriate treatments. By focusing on priorities that matter most to patients and their families, palliative care has been shown to improve quality of care and quality of life, and to generate reductions in avoidable spending.

The COVID-19 pandemic has demonstrated that access to high-quality palliative care and hospice is essential to the well-being of our citizens and our healthcare system.

Interdisciplinary teams, which are a hallmark of palliative care and hospice, are on the front lines caring for affected patients – managing a wide array of symptoms (including breathlessness commonly seen in COVID-19), supporting shared decision-making, supporting family members, and coordinating care transitions. Many hospitals have deployed their palliative care experts to emergency departments and intensive care units to optimize communication with families and provide symptom relief. Hospices and community-based palliative care programs are caring for unprecedented numbers of people with serious illness, reducing the risk of community spread and easing pressure on overburdened hospitals. Palliative care professionals have provided incomparable emotional support to patients and families, helping them navigate excruciating decisions and facilitating connections between loved ones despite the challenges presented by the need for social distancing.<sup>1</sup> Members of the palliative care team, especially social workers and chaplains, often take the lead in providing much needed support to staff to reduce burnout.

Despite our field’s positive impact on patient and family quality of life – both prior to and during the COVID-19 pandemic – hospice and palliative care programs face real threats to their survival. With hospital revenue threatened, our Coalition is concerned that staff furloughs and layoffs are becoming commonplace and are including palliative care team members. In the community, continued lack of reliable financing restricts access to community-based palliative care while inadequate education and training and concerns regarding vaccine access and distribution continue to threaten the adequacy of the workforce. Without continued and expanded investment in hospice and palliative care, Americans’ access to high-value care in all settings is jeopardized.

### ***Concern for Health Equity and Reducing Racial Disparities***

Our Coalition seeks to present a united, yet diverse voice to Congress and the Administration on behalf of providers and other professionals who are interested in advocating for equitable healthcare policies and programs that will improve the care of patients and families living with serious or life-threatening illnesses. As you consider all healthcare legislation and regulations over the coming years, we urge you to consider the impacts of these policies on diverse communities and the imperative to reduce health inequities and disparities that the COVID-19 epidemic has further exposed.

Additionally, as a Coalition representing physicians, nurses, physician assistants, social workers, chaplains, and pharmacists, we want to ensure that Congress and the Department of Health and Human Services are fully aware that this pandemic has not only impacted patients disproportionately, but has also impacted the healthcare workers of color in disproportionate ways, with one recent study finding providers from diverse communities were more than twice as likely as their white counterparts to test positive for the virus.<sup>2,3</sup>

As Congress considers additional legislation responding to this global pandemic, our Coalition urges you to adopt the recommendations outlined below, which would help mitigate the devastating impact of the pandemic on patients and families fighting COVID-19 and the healthcare professionals caring for them.

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<sup>1</sup> <https://wamu.org/story/20/05/04/patients-dying-fast-and-far-from-family-challenge-practice-of-palliative-care/>

<sup>2</sup> [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(20\)30164-X/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(20)30164-X/fulltext)

<sup>3</sup> <https://khn.org/news/article/covid-decimated-our-staff-as-the-pandemic-ravages-health-workers-of-color-in-us/>

## **EXECUTIVE SUMMARY**

The Coalition recommends the following actions to assist American families facing serious illness and strengthen the value of healthcare delivery:

### **Priorities to Address the COVID-19 Crisis**

- Create a National Grief Strategy that will help ensure that all Americans could access timely and culturally sensitive grief support services in their communities. This strategy should include a new grant program to expand grief and bereavement services to assist both American families and healthcare workers in recovery (legislation and/or regulation).
- Ensure adequate supplies and vaccine for all healthcare workers, including those in hospice (legislation and/or regulation).
- Ensure information about and access to the vaccine is targeted to the hardest-hit communities, including diverse communities (legislation and/or regulation).
- Ensure that mental health and emotional resiliency resources are available to healthcare workers, including the palliative care and hospice workforce. This can include grant programs for training in prevention and mitigation strategies, as well as a federal study to identify barriers and facilitators (legislation and/or regulation).

### **Expand Access through Medicare Payment Changes**

- Support access to palliative care via telehealth by making permanent and codifying these key changes: eliminate geographic and originating site restrictions for Medicare reimbursement of telehealth encounters (legislation) and replace arbitrary limits on telehealth visits with medical necessity criteria (regulation).
- Allow Medicare reimbursement for audio-only advance care planning services (HCPCS 99497-99498) (legislation or regulation).
- Eliminate beneficiary cost sharing for patient-centered services such as advance care planning, chronic care management, and cognitive assessment and care planning (legislation).
- Allow hospice-eligible Medicare beneficiaries to elect the hospice benefit concurrent with the SNF skilled benefit (legislation).
- Based on the success of the Medicare Care Choices Model (MCCM), change the Medicare hospice statute to allow for concurrent curative care and hospice benefits (legislation).
- Develop a new community-based palliative care Medicare model or demonstration with key expansions from the MCCM and the upcoming Seriously Ill Population option under the Primary Care First Model (legislation and/or regulation).

### **Expand Access through Medicare Workforce Regulation Changes**

- Allow the use of telehealth for face-to-face visits in hospice and home health care, allow appropriate supervision to occur virtually, and establish modifiers to enable reporting telehealth visits on claims (regulation).
- Permit physician assistants to perform the hospice face-to-face encounter required for the third and subsequent recertification hospice benefit periods (regulation).
- Expand reporting of hospice visits to include chaplains/spiritual counselors (regulation).

### **Preserve Access to Opioids for the Seriously Ill Population**

- Review policies that limit opioid production, availability, and/or dosage and duration for unintended consequences on people living with serious illness (regulation).

### **Build and Sustain the Hospice and Palliative Care Workforce**

- Pass the Palliative Care and Hospice Training and Education Act (S. 2080/H.R. 647, 116th Congress) (legislation).
- Increase investment in the Nursing Workforce Development programs under Title VIII of the Public Health Service Act (PHSA) (legislation).
- Further expand graduate medical education (GME) residency slots and ensure that the allocation aligns with identified workforce shortages, such as Hospice and Palliative Medicine (note that the Resident Physician Shortage Reduction Act (H.R. 1763/S. 348, 116th Congress) makes such provisions) (legislation).
- Ensure adequate support for the Children’s Hospitals Graduate Medical Education (CHGME) program to encourage training for those specializing in pediatric palliative care (legislation and/or regulation).
- Include palliative care curricula in all appropriate GME programs to ensure that future health professionals can support person-centered care (regulation).

### **Bolster Palliative Care Research**

- Create and implement a National Institutes of Health (NIH) trans-institute strategy to ensure dedicated funding for palliative care and end-of-life care (legislation and/or regulation).
- Increase NIH early career development awards for early-stage investigators in palliative care (legislation and/or regulation).
- Ensure that professionals with palliative care expertise are included on relevant Center for Scientific Review (CSR) study sections within the NIH (sub-regulatory).

### **The information that follows provides more information on these recommendations.**

## **I. COVID-19 ESSENTIAL PRIORITIES**

The Administration and Congress have correctly focused on the need to take swift and comprehensive action to end the COVID-19 pandemic. To that end, our Coalition recommends the following specific priorities for inclusion in the next COVID-19 relief package, which has been cited as a priority during the first 100 days of the new Biden-Harris Administration, and in future healthcare policies.

### **A. Protect Care for Patients, Families, and Staff During COVID-19 Pandemic – Vaccine Access and Distribution**

The Coalition, like all Americans, is relieved and encouraged that COVID-19 vaccines are now available and has [urged](#) all hospice and palliative care providers, patients, families and caregivers to receive a COVID-19 vaccination unless otherwise contraindicated.<sup>4</sup>

**Recommendation:** Congress must fund and improve coordination to ensure adequate and equitable access to COVID-19 supplies/testing and, most importantly, vaccines to ensure the safety of all frontline healthcare workers and the patients, caregivers and families they serve, including those in hospice.<sup>5</sup> Further, we strongly recommend that access to, distribution of, and communication regarding the vaccine include a special focus on populations most severely impacted.

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<sup>4</sup> <https://www.nationalcoalitionhpc.org/wp-content/uploads/2020/12/NCHPC-Statement-of-Support-re-COVID-Vaccination-12-23-20.pdf>

<sup>5</sup> <https://www.nhpco.org/support-prioritization-of-vaccine-access/>

## **B. Expand Support and Funding for Grief and Bereavement Services**

The need for grief support will continue to increase as our nation comes to terms with more than 450,000 COVID-19-related deaths to date. We must underscore that widespread grief, loss, and psychological pain will continue impacting individuals, families, communities, and various workplace settings for years to come. The death experience during COVID-19 has been different and traumatic. We know that many people will experience complicated grief, which persists longer and is more intense when other factors such as social isolation and psychosocial vulnerabilities are concurrent. Additionally, healthcare professionals in nursing homes, hospitals and other healthcare settings have experienced extensive loss while caring for patients and are themselves in need of bereavement support.

Hospices and other providers serve as expert sources for grief and psychosocial support in the community for those experiencing grief and loss. These providers, specifically social workers, chaplains, and bereavement counselors have the necessary tools, skills, and experience to help individuals, families, and communities heal. Current systems in place have gaps in providing grief support in our communities. There is a need for new and sustainable funding to expand services, collaboration to identify best practices, and research to understand pandemic-related grief.

**Recommendation:** Hospice and palliative care providers, who have been trained to provide grief and bereavement support, should be deployed as needed as our nation faces the consequences and unprecedented mortality of the COVID-19 pandemic. Our Coalition strongly recommends that Congress and the Administration support the creation of a National Grief Strategy that would help ensure that all Americans could access timely and culturally sensitive grief support services in their communities to meet the increased needs due to the pandemic. This strategy should include the consideration of the establishment of a new grant program to expand grief and bereavement services to assist both American families and healthcare workers in recovery.

## **II. ACCESS AND PAYMENT TO SUPPORT CARE OF THE SERIOUSLY ILL**

Despite the benefits to patients, families, clinicians, and payers,<sup>6</sup> reliable access to hospice and palliative care remains the exception rather than the norm. Implementing the recommendations below will help ensure person-centered care and improved quality of life for the millions of Americans living with serious illness and those who care for them.

### **A. Support Telehealth for Medicare Beneficiaries and All Patients**

The Medicare flexibilities introduced during the COVID-19 public health emergency (PHE) have enabled increased access to critical services for beneficiaries.<sup>7,8,9</sup> A January 2021 survey of palliative care programs by the Center to Advance Palliative Care found that 87% are now delivering patient care via telephone or audio/visual technologies. These programs report 15-20% increases in the number of patients seen, including reaching new patient populations in the home setting (44%), the emergency department (25%), and long-term care settings (20%). A separate survey of hospice providers conducted in May 2020 by the National Association for Home Care & Hospice (NAHC) found that more than 95% of responding hospices were unable to provide in-person visits to patients due to the risks associated with COVID-19 transmission. As a result, hospices have incorporated the use of telecommunications into

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<sup>6</sup> <https://www.capc.org/the-case-for-palliative-care/>

<sup>7</sup> Palliative Care Takes to Telemedicine in COVID Crisis, MedPage Today, May 5, 2020.

<sup>8</sup> <https://www.kqed.org/news/11810405/palliative-care-doctors-turn-to-technology-to-help-those-dying-alone>

<sup>9</sup> <https://www.johnahartford.org/blog/view/is-availability-of-telehealth-for-older-adults-a-covid-19-silver-lining>

their daily operations and have found that their use has supported the delivery of high-quality care. Use of such technologies has also been received favorably by patients and their family members, although disparities in access to telehealth persist.<sup>10</sup>

**Recommendations:** To maintain these gains, Congressional action is needed to address underlying barriers to telehealth, such as Medicare law and the uneven state of broadband capabilities across the country. Specifically:

- **Eliminate currently legislated geographic and originating site restrictions.** Healthcare delivery during the COVID-19 pandemic has proven that telehealth can be provided safely and effectively when the patient is in the home, and that urban, suburban, and rural areas alike all benefit from telehealth services. This recommendation is consistent with conclusions from the Taskforce for Telehealth Policy, the American Hospital Association, and many other healthcare organizations.
- **Invest in the required broadband infrastructure where sufficient capacity is lacking.** There are an estimated 18 million people living in parts of the United States without reliable access to online services,<sup>11</sup> greatly reducing their access to palliative care as well as other vital healthcare services virtually. The 2020 FTC Telehealth grant program under the CARES Act has successfully expanded access in some communities, but more is needed.

**Additionally, the Coalition recommends** that the following modifications to telehealth policy (which were established as part of the COVID-19 PHE measures) be made permanent:

- *For all telehealth services:*
  - **Allow audio-only advance care planning services (99497-99498)** for both new and established patients. Advance care planning services are fully conversational, and requirements for video capability can become a barrier in some circumstances. Note that this is currently allowable under the PHE flexibilities but is set to terminate once the emergency ends.
  - **Eliminate unnecessary telehealth frequency limits.** Person-centered care would preclude arbitrary limits on telehealth visits. Instead, their frequency should be based on medical necessity and the acuity of illness.
- *For hospice and palliative care clinician services:*
  - **Allow for supervision via communications technologies.** Consideration should be given to allowing for direct supervision via virtual presence following the end of the PHE, to allow for the collection of valuable data about the benefits and risks.
- *For hospice services:*
  - **Allow the use of telehealth for face-to-face visits required for the recertification of a beneficiary for the hospice benefit. Additionally, permit use of audio-only telecommunications technology under exceptional circumstances (where access to audio-video is not available and in-person visits would risk harm to the patient or practitioner).**

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<sup>10</sup> <https://healthlaw.org/will-telehealth-provide-access-or-further-inequities-for-communities-of-color/>

<sup>11</sup> Representative Roger Williams (R-TX) press release, October 20, 2020. Accessed 11/21/20

- **Establish modifiers that allow for reporting of technology-based hospice visits on claims.** This will ensure that claims data fully reflects interactions between the various hospice disciplines and patients/family members and allow CMS to assess the impact of technology-based visits on quality of care.
- **Expand reporting of hospice visits (in-person and virtual) to include chaplains/spiritual counselors, and other appropriate disciplines.**
- *For home health services:*
  - **Allow the use of telehealth for home health face-to-face certification and recertification, including use of audio-only visits where necessary.**
- *For home health and hospice services:*
  - **Provide financial assistance to hospices and home health agencies to encourage the adoption of certified Electronic Health Records (EHR)** and ensure improved communication and coordination of care. Such assistance could include incentives such as small business loans, tax incentives, and grants from the Medicare and Medicaid programs and other private sector solutions. Earlier EHR incentive programs had been unavailable to hospices and home care agencies, which has resulted in significant uneven adoption that is currently thwarting efforts for interoperability and effective care coordination.

## **B. Improve Medicare Part B**

While telehealth reimbursement is necessary for improved access to palliative care services, that alone is insufficient to ensure access to palliative care for all Medicare beneficiaries who can benefit. Cost-sharing, billing limitations, and other features of current law and regulation create barriers for patients who are most in need.

**Recommendations:** The Coalition urges the following modifications:

- **Eliminate beneficiary cost sharing for patient-centered services such as advance care planning, chronic care management, and cognitive assessment and care planning,** and evaluate the impact of these changes. Beneficiary copayments have been identified by clinicians and patients alike as a barrier to accessing palliative care.<sup>12</sup> Previous legislation has successfully removed beneficiary cost sharing for high-value services such as evidence-based screenings and immunizations and could be replicated for services such as advance care planning.
- **Increase valuation of home and domiciliary evaluation and management (E/M) visits.** CMS finalized an increase in the valuation of office/outpatient E/M visit code set (CPT codes 99201-99215) consistent with recommendations from the AMA RVS Update Committee (RUC), effective starting calendar year 2021. However, CMS did not concurrently increase the valuation of home-based visits, which are analogous to office/outpatient visits, and often generate tremendous value to the healthcare system. Updating values of home and domiciliary E/M visits in a manner consistent with CMS' policies for office and outpatient E/M visits must be the policy going forward.

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<sup>12</sup> D'Ambruoso SF, Walling AM. Copayments May Be a Barrier to Concurrent Clinic-Based Palliative Care. J Palliat Med. 2018 Jun;21(6):744

### C. Improve Medicare Part A

Home health and hospice benefits are essential for optimizing the quality of life for Medicare beneficiaries living with serious illness.

**Recommendations:** The following actions will strengthen both access to and quality of these services:

- **Permit physician assistants (PAs) to perform the hospice face-to-face encounter for the purposes of hospice recertification.** Recent legislative changes permit PAs to serve as a hospice patient’s attending physician, but statute still prohibits PAs from performing the hospice face-to-face recertification encounter.
- **Allow terminally ill Medicare beneficiaries to elect their Medicare Hospice Benefit concurrently with the SNF skilled benefit** if eligible, without financial penalties to the patient and family. This can enable hospice care during post-acute stays, addressing unmet needs and potentially avoiding hospital transfers.

### D. Preserve Access to Opioids for the Seriously Ill Population

Our Coalition appreciates that our nation is facing a public health crisis characterized by staggering rates of opioid use disorder and overdose death. At the same time, we must consider how best to ensure that the millions of patients with pain receive high-quality care, including treatment with opioids when they are medically indicated and can be taken safely. We are particularly concerned that, in recent years, efforts to curb the opioid epidemic have yielded numerous federal and state reforms designed to address inappropriate use of controlled substances, some of which have unnecessarily restricted access to pain medications for patients with serious illness or those who are in hospice care.

**Recommendation:** The Coalition urges Congress and CMS to apply caution to further efforts to curtail use of controlled substances and urges appropriate consideration be given to patients receiving palliative and hospice care to ensure timely access to such medications and to limit prescriber burden. We are especially concerned about policies that limit opioid production, availability, and/or dosage and duration of prescriptions and would impede the individualization of treatment to patient needs.

## III. NEED FOR COMMUNITY-BASED PALLIATIVE CARE MODELS AND DEMOS

Our Coalition supports the utilization of payment and care models to demonstrate the value of person-centered care that people with serious illness need now more than ever. Initiation of a successful Medicare demonstration at the Centers for Medicare & Medicaid Services could allow every Medicare beneficiary to benefit from high-quality serious illness care at any time during their disease progression and not just at the end of life.

### A. Expand on the Medicare Care Choices Model (MCCM)

The MCCM model, operated by the Center for Medicare and Medicaid Innovation (CMMI), has provided an important opportunity to test community-based palliative care in a limited and targeted fashion (beneficiaries must be hospice-eligible), with outcomes demonstrating the effectiveness of “supported



care services” and concurrent curative care in improving quality and reducing costs.<sup>13</sup> According to this most recent CMMI evaluation report for MCCM, it was found that the supported care services in MCCM “led to a 25 percent decrease in total Medicare expenditures” and resulted in earlier hospice elections”.<sup>14</sup>

**Recommendation:** To build on the success of MCCM in improving quality and reducing costs, the Coalition recommends and urges Congress to make a conforming change in the hospice statute to allow for this concurrent curative care to be furnished to patients earlier in the disease process.

## **B. Create a New Community-Based Palliative Care Demonstration Model**

People with serious illness and their families and caregivers require interdisciplinary care, which is now available in their home and communities but not broadly covered by Medicare outside of demonstrations. Expertise in patient and family education, care planning and coordination, pain and symptom management, support for functional needs, enhanced telehealth services, interdisciplinary care, psychological, social and spiritual support, and co-management with other medical providers make hospice and palliative care providers ideal to deliver this model of care in support of people and families dealing with serious illness at home.

**Recommendation:** Our Coalition urges Congress and CMMI to support and fast-track development of a new Community-Based Palliative Care (CBPC) [Demonstration](#) for people with serious illness, to provide essential interdisciplinary care in their homes.<sup>15</sup> This would be significantly different than the Primary Care First-Seriously Ill Population Model (PCF-SIP) currently underway at CMMI as PCF-SIP has significant geographic limitations, limits beneficiary access to model benefits, and requires fragmentation of care. There is a significant need for a CMMI-supported CBPC effort that would lead to improved quality and cost outcomes for beneficiaries experiencing serious illness. This is especially important for seriously ill patients with comorbidities who are at higher risk when battling conditions such as COVID-19.

Our Coalition has drafted a framework for a CBPC model aimed at improving patient outcomes and experience of care and reducing avoidable and potentially harmful emergency department visits and hospitalizations for high-risk patients.<sup>16</sup> We look forward to working with the new Administration and Congress on securing this much needed care for America’s seniors in their homes.

## **IV. BUILDING AND SUSTAINING THE WORKFORCE**

Policymakers can help build a healthcare workforce more closely aligned with the nation’s evolving healthcare needs through efforts to close the large gap between the number of health professionals with palliative care training and the number required to care for the expanding population of patients with serious illness or multiple chronic conditions. Indeed, the National Academy of Sciences, Engineering and Medicine (NASEM) and the Medicare Payment Advisory Commission (MedPAC) have highlighted the need to increase education and training opportunities for those caring for patients with

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<sup>13</sup> <https://innovation.cms.gov/innovation-models/medicare-care-choices>

<sup>14</sup> <https://innovation.cms.gov/data-and-reports/2020/mccm-fg-thirdannrpt>

<sup>15</sup> [https://www.nationalcoalitionhpc.org/wp-content/uploads/2020/09/CBPC\\_sign-onz-letters.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2020/09/CBPC_sign-onz-letters.pdf)

<sup>16</sup> [https://www.nationalcoalitionhpc.org/wp-content/uploads/2021/01/Coalition-NHPCO-CBPC-Demo\\_One-Page\\_-2020-F.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2021/01/Coalition-NHPCO-CBPC-Demo_One-Page_-2020-F.pdf)

serious illness.<sup>17</sup> And the COVID-19 pandemic has only served to shine a bright light on the critical need to address the palliative care workforce shortage.

We are very grateful that Congress, as part of the Consolidated Appropriations Act 2021, acted to expand federal funding for graduate medical education (GME) for the first time in nearly 25 years by including 1,000 new Medicare-funded residency slots. However, narrowing the current and projected healthcare workforce gap to address the growing number of patients with serious illness will require both a further increase in graduating clinicians and training more academic faculty to teach and train future health professionals in palliative care.<sup>18</sup> At the same time, meaningful supports are essential to sustaining this workforce, including to address clinician wellbeing and provide enhanced mental health resources for those on the frontlines of the COVID-19 pandemic.

### **A. Improving Serious Illness Care through Education, Training, and Supports**

**Recommendation:** Pass the Palliative Care and Hospice Training and Education Act (S. 2080/H.R. 647, 116th Congress), which will:

- Expand opportunities for interdisciplinary education and training in palliative care and end-of-life care through the establishment of education centers and career incentive awards for physicians, nurses, advanced practice nurses, and social workers, and other health professionals.
- Enhance existing health professions education programs by providing incentives to incorporate palliative care and hospice training.

### **B. Increase Investment in the Nursing Workforce Development Programs Under Title VIII of the Public Health Service Act (PHSA)**

**Recommendation:** Help meet the nation's demand for nursing services by addressing all aspects of nursing education, practice, recruitment, and retention through the Title VIII Nursing Workforce Development programs.

### **C. Support Graduate Medical Education (GME)**

**Recommendation:** The Coalition urges Congress and CMS to:

- Further increase the number of residency slots funded by Medicare and ensure distribution of these positions address specialty shortages, as provided in the bipartisan *Resident Physician Shortage Reduction Act* (H.R. 1763/S. 348, 116<sup>th</sup> Congress). Hospice and Palliative Medicine (HPM) fellowship training programs are not eligible to receive federal funds since HPM was recognized as a formal subspecialty in 2006, and Medicare GME funding was capped in 1997. This cap should be updated to address evolutions in medicine and patient needs, especially given the current demographics and demands.

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<sup>17</sup> <https://www.nap.edu/catalog/25789/building-the-workforce-we-need-to-care-for-people-with-serious-illness>

<sup>18</sup> <https://www.healthaffairs.org/doi/10.1377/hlthaff.2019.00018>

- Ensure adequate support for the Children’s Hospitals Graduate Medical Education (CHGME) program to encourage training for those specializing in pediatric palliative care.
- Include palliative care curricula in all appropriate GME programs to ensure that future health professionals in other fields are equipped with the skills to diagnose and treat pediatric or adult patients with serious illness.

#### **D. Provide Adequate Mental Health Resources to Support the Interdisciplinary Palliative Care and Hospice Workforce**

Members of palliative care and hospice interdisciplinary teams play an essential role in times of crisis, including the ongoing COVID-19 PHE. Many on the front lines have experienced post-traumatic stress disorder and moral distress, and the long-term impact on palliative care professionals is unknown. Clinician wellness must be a priority in policies to respond to workforce shortages.

**Recommendation:** The Coalition urges Congress and CMS to:

- Establish federal grants for training health profession students, residents, or healthcare professionals in evidence-informed strategies to reduce and prevent suicide, burnout, mental health conditions, and substance use disorders. The Dr. Lorna Breen Health Care Provider Protection Act (S.4349/H.R. 8094, 116<sup>th</sup> Congress) provides a framework for such action.
- Establish a voluntary grant program within the Department of Health and Human Services to allow healthcare employers or facilities to confidentially assess and treat the mental health of healthcare workers on the front lines of treating COVID-19 patients.
- Fund a comprehensive study within the Department of Health and Human Services on healthcare worker mental health, with a focus on identifying the organizational, systemic, and occupational factors that contribute to distress and burnout and the barriers to seeking and accessing mental health treatment; the ramifications for the healthcare system and patient outcomes; and the best ways to prevent and address these problems. The study should prioritize finding ways to mitigate the long-term mental health impacts on healthcare workers who treated COVID-19 patients. Numerous members of Congress have already expressed support for these proposed actions.<sup>19</sup>

## **V. RESEARCH**

Unlike other areas of medicine, the research base to support the basic elements of palliative care clinical practice (i.e., pain and symptom management, communication skills, care coordination) is small, underfunded, and inadequate.<sup>20</sup> Fewer than 1% of all grants awarded overall by the National Institutes of Health (NIH), including at the National Cancer Institute (NCI), National Heart Lung Blood Institute (NHLBI), National Institute of Diabetes, Digestive and Kidney Disease (NIDDK), and the National Institute of Neurological Disorders and Stroke (NINDS) – four of the largest Institutes and those representing six of the eight leading causes of death in the United States, excluding accidents – were awarded to

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<sup>19</sup> <https://krishnamoorthi.house.gov/sites/krishnamoorthi.house.gov/files/2020.05.04%20HCW%20Mental%20Health%20-%20Pelosi%20McCarthy%20-%20Final.pdf>

<sup>20</sup> A Systematic Review in Support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition

investigators performing palliative care research. These percentages have remained unchanged for over 15 years. Meanwhile, in 2018, the Labor and Health and Human Services (L/HHS) Appropriations bill urged the NIH to expand and intensify national research programs in palliative care to address quality of care and quality of life for the rapidly growing population of individuals in the United States living with a serious illness.

### **A. Create and Implement a Trans-Institute Research Strategy at the NIH**

The establishment of a trans-Institute investment in palliative care and end-of-life care will allow for dedicated and targeted funding for palliative care research.

**Recommendation:** Congress should request a report from the NIH in response to the 2018 Labor HHS Appropriations bill to determine how NIH has implemented the recommendations to expand and intensify palliative care research efforts. The Coalition urges Congress to request NIH develop a trans-institute strategy which is needed to strengthen clinical practice and healthcare delivery and yield meaningful evidence for improving quality of life for patients with many types of serious illness (hence the need for a *trans-institute strategy*). The disease-specific structure of NIH and the lack of targeted funding for palliative care research has caused palliative care research funding to languish. Palliative care’s attention to the whole person and family, as well as its focus on multiple diseases and conditions, and persons of any age leaves it orphaned by the current family of NIH Institutes.

### **B. Increase NIH Career Development Awards for Early-Stage Investigators**

A major barrier to the growth of palliative care is the lack of a pipeline for the development of scientific investigators. Historically, externally funded research by senior investigators has cross-subsidized mentoring and pilot studies for their mentees, which helped to establish a mentee’s publication track record and provided access to data to support NIH career development award proposals (e.g., K awards).

**Recommendation:** Create a career development award program modelled after NIA’s Paul B. Beeson Emerging Leaders Career Development Award in Aging (K76). Such an award should be supported by a consortium of relevant Institutes and Centers including NIA, NINR, NCI, NHLBI, NIDDK, NINDS and NIMH and could support 15-18 early-stage investigators per year with specific funding dedicated to pediatric and geriatric palliative care.

### **C. Ensure Palliative Care Expertise on NIH Scientific Review Sections**

Palliative care professionals bring a valuable perspective on the experiences of patients and families facing serious illness and the opportunities to optimize quality of life that should inform research agendas and priorities.

**Recommendation:** Include professionals with palliative care expertise on relevant Center for Scientific Review (CSR) study sections within the NIH. Additionally, involve appropriate palliative care ad hoc reviewers in relevant reviews when standing study section expertise is lacking.

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Thank you for all your work to address the current and ongoing pandemic facing the nation and for your consideration of these urgent COVID-19 priorities and for consideration of our long-term healthcare policy recommendations. Our Coalition is pleased to offer the expertise of our members and look

forward to working with you and your staff as you work on tackling the nation's most pressing healthcare challenges. If you have any questions, please contact Amy Melnick, Executive Director, at 202-306-3590 or [amym@nationalcoalitionhpc.org](mailto:amym@nationalcoalitionhpc.org).

Signed,

American Academy of Hospice and Palliative Medicine (AAHPM)  
Association of Professional Chaplains (APC)  
Center to Advance Palliative Care (CAPC)  
Health Care Chaplaincy Network (HCCN)  
Hospice and Palliative Nurses Association (HPNA)  
National Association for Home Care & Hospice (NAHC)  
National Hospice and Palliative Care Organization (NHPCO)  
National Palliative Care Research Center (NPCRC)  
Palliative Care Quality Collaborative (PCQC)  
Physicians Assistants in Hospice and Palliative Medicine (PAHPM)  
Social Work Hospice and Palliative Care Network (SWPHN)  
Society of Pain and Palliative Care Pharmacists (SPPCP)