



AMERICAN ACADEMY OF
HOSPICE AND PALLIATIVE MEDICINE

American Academy of Hospice and Palliative Medicine
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Written Public Testimony Prepared for the House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Fiscal Year 2026 Appropriations for the National Institutes of Health/National Institute on Aging
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Chairman Aderholt, Ranking Member DeLauro, and members of the Subcommittee, the American Academy of Hospice and Palliative Medicine (AAHPM or Academy) appreciates the opportunity to provide written public testimony and stands ready to work with the Subcommittee to advance sound policy that improves care and quality of life for millions of Americans facing serious illness, along with their families and caregivers. We greatly appreciate your leadership investing in palliative care research and thank you for including \$12.5 million in the *Further Consolidated Appropriations, 2024* for the National Institute on Aging (NIA) to implement a multi-Institute, multi-disease strategy to focus, expand, and intensify a national research program in palliative care. **In fiscal year (FY) 2026, AAHPM requests \$12.5 million for the NIA to continue to coordinate the work of the multi-disease Consortium for Palliative Care Research Across the Lifespan.** Ongoing bipartisan, bicameral, and steadfast leadership has been instrumental in realizing this step to strengthen the commitment to support patients facing serious illness and their families. **AAHPM also requests that you prioritize robust funding of at least \$51.303 billion for the National Institutes of Health (NIH) in FY 2026, and ensure NIH facilities and administrative cost reimbursements are sufficient to cover the true costs of conducting research.**

AAHPM is the professional organization for physicians specializing in Hospice and Palliative Medicine. Our more than 5,200 members also include nurses, social workers, spiritual care providers, and other health professionals deeply committed to improving quality of life for the expanding and diverse 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 timely access to high-quality, equitable palliative and hospice care. For more than 30 years, AAHPM has been dedicated to advancing the discipline of Hospice and Palliative Medicine through professional education and training, development of a specialist workforce, support for clinical practice standards, research, and public policy.

BACKGROUND

Palliative care is an interdisciplinary model of care aimed at preventing and treating the debilitating effects of serious and chronic illness – such as cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer’s, ALS, and MS – and involves the relief of pain and other symptoms that cause discomfort, such as shortness of breath and unrelenting nausea. Palliative care is patient- and family-centered – it focuses on matching treatment to achievable patient goals and supporting patients and their families/caregivers during and after treatment to maximize quality of life. In practice, this involves detailed and skilled communication with patients and families to elicit goals and preferences; expert assessment and management of physical, psychological, and other sources of suffering; and coordination of care across the multiple settings (e.g., hospital, post-acute care, ambulatory clinics, home) that patients can often traverse throughout the course of a serious illness. Palliative care can be provided from the time of diagnosis and offered alongside life-prolonging and curative therapies for individuals living with serious, complex, and eventually terminal illness. Hospice care is palliative care tailored for individuals near the end of life.

AAHPM believes that palliative care providers and organizations, including hospices, are integral to meeting the “triple aim” of better care for individuals, improved health of populations, and lower growth in health care expenditures. Indeed, the National Priorities Partnership has highlighted palliative and end-of-life care as one of six national health priorities that have the potential to create lasting change across the U.S. health care system.

An expanding body of medical research has documented the benefits of high-quality palliative and hospice care for patients and families, for hospitals and payers, and for the health care system as a whole.¹ Palliative care is associated with enhanced quality of life for patients, higher rates of patient and family satisfaction with medical care, reduced hospital expenditures and lengths of stay, and other positive outcomes – including longer patient survival time. Furthermore, palliative care achieves these outcomes at a lower cost than usual care, by helping patients to better understand and address their needs, choose the most effective interventions, and avoid unnecessary/unwanted hospitalizations and interventions. Hospice care has also been associated with lower cost of care, better outcomes (such as relief of pain), and even longer life, despite its focus on comfort rather than treatment aimed at cure.

Still, too many patients with serious illness experience tremendous physical and psychosocial suffering and, unlike areas of medicine focused on curing or preventing disease, the evidence base for relieving suffering and improving quality of life for seriously ill patients and their caregivers is inadequate.^{2,3} To ensure that the millions of Americans with serious illness and their families/caregivers receive the high-quality care that they need and deserve, more research is needed to better understand and address pain and other distressing symptoms related to serious illness, and to improve serious illness care delivery models, communication science, and caregiving science. We also know there are significant disparities in palliative and end-of-life care. New research holds the potential to reduce these disparities in the care of people living with serious illness and their families by integrating historically excluded patients and examining the role of social determinants of health — which for palliative care include loneliness, food access, poverty and financial toxicity, and insufficient or unsafe housing — in care delivery, quality, and outcomes.⁴

The FY 2025 Labor, Health and Human Services, Education, and Related Agencies (LHHS) Subcommittee funding bill assumed reorganization of the NIH, including changing the NIA into the National Institute on Dementia. We are concerned that this change would significantly narrow the scope of the Institute, suggesting an exclusive focus on dementia no longer inclusive of vital topics that aging adults face unrelated to dementia such as frailty, caregiver research, falls, palliative care needs and delivery, polypharmacy, and medical decision making. Collapsing institutions with a strong scientific mission risks a loss of rigorous scientific proposals directly addressing specific value areas. Solely focusing the Institute on dementia would fail to support the many other aging issues that require coordination across institutes.

The U.S. Census Bureau projects that the population aged 65 and over will approximate 83.7 million by 2050, almost double that in 2012. As the population ages, the number of people living with serious, complex, and chronic illness will continue to grow. Many of the problems of our health care system – high costs, overutilization, lack of coordination, preventable transitions between healthcare institutions, and poor quality – become particularly evident during extended chronic and serious illness. We believe palliative care offers the solution and we strongly support the leadership of the NIA related to coordination of the multi-Institute palliative care research. **We urge you to retain NIA’s focus on vital topics that impact aging adults, such as palliative care research, and not focus solely on dementia.**

FY 2026 APPROPRIATIONS FUNDING AND REPORT LANGUAGE REQUESTS

Research related to palliative care and serious illness crosses nearly every Institute, Center, and Office (ICO) at the NIH, but also poses challenges because it does not fit neatly within a single ICO. The Academy appreciates that Congress included report language urging the NIH to develop a multi-Institute strategy for increasing funded research in palliative care for persons living with chronic and advanced illness in the LHHS appropriations reports in FY 2011, FY 2019, the *Consolidated Appropriations Act, 2023*, and the *FY2024 Further Consolidated Appropriations Act*. We are optimistic that maintaining support for the Consortium for Palliative Care Research Across the Lifespan will help improve coordination and expand activities related to palliative care research across NIH.

AAHPM believes that the scientific work of the NIH must be maintained and requests that you prioritize robust funding of at least \$51.303 billion for the NIH in the FY 2026 LHHS Subcommittee funding bill. The growth and success of serious illness research over the past 20 years has been a major achievement, and reductions in NIH funding would be catastrophic for patients and their families. Beyond this immediate impact, reductions in NIH funding would threaten the United States' leadership in biomedical research. NIH-funded scientists have led ground-breaking discoveries in pain management, cancer, advanced organ diseases, stroke, and childhood illnesses, dramatically improving both quality and longevity of life. The NIH funding awarded to researchers also produces important economic returns, including supporting more than 400,000 jobs and roughly \$93 billion in economic activity in the U.S.⁵

As you may know, NIH indirect costs cover essential research-related expenses, including biomedical laboratories, data processing and storage, grant financial management, electricity and

computing infrastructure, and administrative support. Therefore, **we ask you to ensure that NIH grants include adequate and evidence-based indirect cost support, and place the burden of reporting indirect costs on the recipient entities and not individual researchers.** The ability of millions of Americans to live well, remain productive, and continue working into their seventies and eighties is a direct result of NIH-funded science. Reducing NIH resources without an immediate, sustainable funding alternative would cripple our world-leading biomedical research program.

For FY 2026, AAHPM requests that the Subcommittee continue the \$12.5 million in the LHHS Subcommittee funding bill for the NIA and the multi-Institute, multi-disease Consortium for Palliative Care Research Across the Lifespan and offer the language below for consideration as part of the report to accompany the FY 2026 LHHS appropriations:

Palliative Care Research.—The Committee continue the \$12,500,000 for NIA to coordinate the work of the Consortium for Palliative Care Research Across the Lifespan, including developing early and mid-stage researchers, and engaging various healthcare systems, providers, and community partners. The Committee recognizes that palliative care is a critical area of research and informs supportive care for patients of all ages with serious illness and their families focused on relief of symptoms and suffering, communication of prognosis and treatment options in the context of patient goals, and coordination of care within and across health care settings.

The Academy thanks the Subcommittee for previous report language and funding, and requests support in the FY 2026 LHHS bill to continue NIH's efforts to realize the goal of enhancing palliative care research to improve care and quality of life for the expanding and diverse population of patients with serious illness, as well as their families and caregivers.

REFERENCES

¹ "The Evidence for High-Quality Palliative Care." American Academy of Hospice and Palliative Medicine. Accessed February 15, 2023. https://aahpm.org/uploads/advocacy/The_Evidence_for_High-Quality_Palliative_Care.pdf

² National Academies of Science Engineering and Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. The National Academies Press; 2015:1-612.

³ Brown E, Morrison RS, Gelfman LP. An Update: NIH Research Funding for Palliative Medicine, 2011-2015. *J Palliat Med*. Feb 2018;21(2):182-187. doi:10.1089/jpm.2017.0287

⁴ "Palliative Care In The Face Of Racism: A Call To Transform Clinical Practice, Research, Policy, And Leadership", *Health Affairs Forefront*, February 9, 2022. doi: 10.1377/forefront.20220207.574426

⁵ United for Medical Research. NIH's role in sustaining the US economy. 2024. Accessed November 1, 2024. <https://www.unitedformedicalresearch.org/wp-content/uploads/2024/03/UMR-NIHs-Role-in-Sustaining-the-US-Economy-2024-Update.pdf>