

February 17, 2017

The Honorable Tom Price, MD
Secretary of the U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

The Honorable David Shulkin, MD
Secretary of the U.S. Department of Veterans Affairs
810 Vermont Avenue, NW
Washington DC 20420

Dear Secretaries Price and Shulkin:

As you begin your tenure in the cabinet, we look forward to working with you and others in the new Administration to improve care for people facing serious illness and those who are near the end of life.

This past fall, The Pew Charitable Trusts convened the undersigned organizations with the goal of developing policy recommendations to address the most pressing issues for seriously ill patients and their families. While our organizations came to the task from different perspectives, we share a common purpose to improve the quality and effectiveness of care provided to patients with serious illness and near the end of life and to contribute to a more sustainable health care system.

The appendix to this letter includes detailed background materials and evidence-based recommendations on how your Departments can lead the way toward better health care for the millions of Americans with serious illness and their families.

These recommendations touch on critical issues: bolstering the health care workforce, innovation around models of care, research to strengthen palliative care and end-of-life care, and better use of technology to ensure patient preferences are honored. Taken together, these recommendations are intended to move the health care system to be more person- and family-centered, and one in which patients are fully informed of their care options, treatment preferences are clearly understood, and tools are provided to honor those preferences, improve quality, and hold the health system accountable. All of our work rests upon rigorous, nonpartisan, evidence-based research, and our ideas draw on the experience of both clinicians and payers.

Key challenges to improving palliative care and end-of-life care include the need to:

- Address the shortage of health care providers trained in palliative care and end-of-life care;
- Establish quality measures to support evidence-based care for seriously ill patients;
- Develop innovative care models and tools to scale and disseminate approaches that have been proven effective
- Expand research to help establish evidence to strengthen clinical practice and improve health care delivery; and
- Ensure access to, and transfer of, documentation of patients’ goals of care across the care continuum and within their health records.

Targeted action by your Departments and the 115th Congress to improve palliative care and end-of-life care has the potential to make a tremendous difference in the lives of seriously ill patients and those at the end of life, their families, and caregivers throughout the country.

We propose the following recommended actions:

Building a Robust Workforce through Education and Training

- Expand opportunities for interdisciplinary education and training in palliative care and end-of-life care through new education centers and career incentive awards for physicians, nurses, advanced practice nurses, social workers, and other health professionals.
- Enhance existing health professions education programs by providing incentives to incorporate palliative care and hospice training, including training focused on care for individuals with cognitive impairment, significant physical or developmental disabilities, or serious mental illness.
- Support reauthorization of nursing workforce programs under Title VIII of the Public Health Service Act (PHSA) and encourage the Health Resources and Services Administration (HRSA) to bolster education in hospice and palliative nursing from primary care to specialty level practice.
- Strengthen the Geriatrics Health Professions Programs under Titles VII and VIII of the PHSA by reauthorizing and expanding the Geriatrics Workforce Enhancement Program (GWEP) and reauthorizing a freestanding Geriatric Academic Career Awards program (GACA) under Title VII.
- Increase the number of residency slots funded by Medicare and ensure that the allocation of new residency slots aligns with identified workforce needs, including Hospice and Palliative Medicine and Geriatric subspecialties.
- Encourage physician and interdisciplinary training programs under Graduate Medical Education (GME) to include hospice and palliative care and geriatrics curricula.

Promoting Measures and Care Models that Improve Quality

- Use a portion of the \$75 million included in the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) to develop palliative care and end-of-life care quality measures for providers treating people with serious illness.
- Revise the Consumer Assessment of Healthcare Providers and System program (CAHPS) to ensure consumer and family feedback on quality of care.
- Direct the Department of Health and Human Services (HHS) to develop patient-centered quality measures that span care settings and take into account patient goals and preferences and the agreement of those with care plans and outcomes.
- Harness the Beneficiary and Family Centered Care Quality Improvement Organizations' expertise to improve the collection and honoring of patient preferences.
- Expand the use of models of care shown to improve quality.
- Expand and refine existing demonstrations and test new care models that offer concurrent hospice and disease-directed care, expand access to palliative care, increase access to advance care planning, and improve patient-centered care for individuals with serious illness.
- Adopt models of public-private partnership that increase access to palliative care and hospice for veterans.

Supporting Research to Strengthen Palliative Care and End-of-Life Care Practice

- Enhance federal research in palliative care and end-of-life care to strengthen clinical practice and health care delivery and yield meaningful evidence for improving patient quality of life.

Improving Health Information Technology to Honor Patients' Preferences

- Direct the Office of the National Coordinator for Health Information Technology (ONC) to create a certified health electronic record technology (CEHRT) standard that requires an immediately-accessible link to any advance care planning document within an electronic health record.

Through new initiatives and rule-making, this Administration has the opportunity to create a more patient-centered health care system that meets the needs of people with serious illness and their families. The concepts underlying these recommendations are not new. There is already bipartisan support in Congress for several bills that were introduced in the 114th Congress: The Palliative Care and Hospice Education and Training Act (PCHETA), the Care Planning Act, the Personalize Your Care Act 2.0, and the Compassionate Care Act. We urge you to work with Congress to enact bills such as these, which would improve the quality of care and quality of life for millions of people with serious illness and their families.

We are eager to provide additional information and to work with your staff on these important regulatory and legislative recommendations. Please contact Lee Goldberg at The Pew Charitable Trusts at lgoldberg@pewtrusts.org or 202-552-2127 to let us know how we might be most helpful. We will also reach out to your staff to see when we might schedule an appointment to discuss our recommendations further.

Sincerely,

American Academy of Hospice and Palliative Medicine

American Cancer Society Cancer Action Network

American Geriatrics Society

American Heart Association/American Stroke Association

Blue Shield of California

Cambia Health Solutions

Center to Advance Palliative Care

Coalition to Transform Advanced Care

Consumer Coalition for Quality Health Care

National Coalition for Hospice and Palliative Care

National Hospice and Palliative Care Organization

National Partnership for Hospice Innovation

National POLST Paradigm

The Pew Charitable Trusts

Currently, millions of Americans are living with serious illness and the number is expected to rise significantly given demographic trends.

Over the next two decades, the number of people over 65 will nearly double to more than 72 million, or one in five Americans, and most people with serious illness will be in this age group.¹ The U.S. health care system, built on treating acute illness and injuries, provides major opportunities to improve care for patients with serious illness and those near the end of life. We must expand the efforts of innovative health care providers and plans that provide person-centered palliative care and end-of-life care, and use advance care planning to ensure seriously ill patients' care goals and treatment preferences are honored.

As members of organizations that have spent years advocating for vulnerable patients and their families, we see an important opportunity to improve the lives of seriously ill patients and their families by providing access to palliative care and ensuring that people near the end of life receive care in the setting of their choice. Bold steps by this Administration and Congress can ensure patients and their families a health system that is more patient-centered and culturally sensitive, that improves the quality of life for seriously ill patients, including those near the end of life, and that is more efficient and accountable, and therefore more sustainable overall.

KEY TERMS

Palliative Care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care addresses physical, intellectual, emotional, social, and spiritual needs and facilitates patient autonomy, access to information, and choice. It is provided by a specially-trained interdisciplinary team of doctors, nurses, social workers, chaplains and other specialists who work together to provide patients with an extra layer of support. It is appropriate at any age and at any stage in a serious illness; is not restricted by prognosis; and can be provided along with curative treatment.

Hospice is a coordinated model for quality, compassionate care for people facing a life-limiting illness. In hospice, an inter-disciplinary team of physicians, nurses, social workers, chaplains, hospice aides, and others provide expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and preferences, while also supporting the patient's family. Medicare covers hospice for individuals who have been certified by two physicians as having a

prognosis of six months or less if the disease follows its normal course, and who agree to forego more aggressive medical treatments. Some private payers have more flexible eligibility criteria.

Serious Illness is a condition that carries a high risk of mortality (though cure may remain a possibility); has a strong negative impact on one's quality of life and functioning in life roles, independent of its impact on mortality; and/or is burdensome in symptoms, treatments, or caregiver stress. This may be experienced as physical or psychological symptoms; time and activities dominated by the illness's treatment; and/or the physical, emotional, and financial stress on caregivers and family. The term "advanced illness" overlaps with serious illness and involves many of the same policy issues.

An Advance Care Plan is any document related to advance care planning: legal documents, medical orders, and notes from conversations between individuals and their health care professionals.

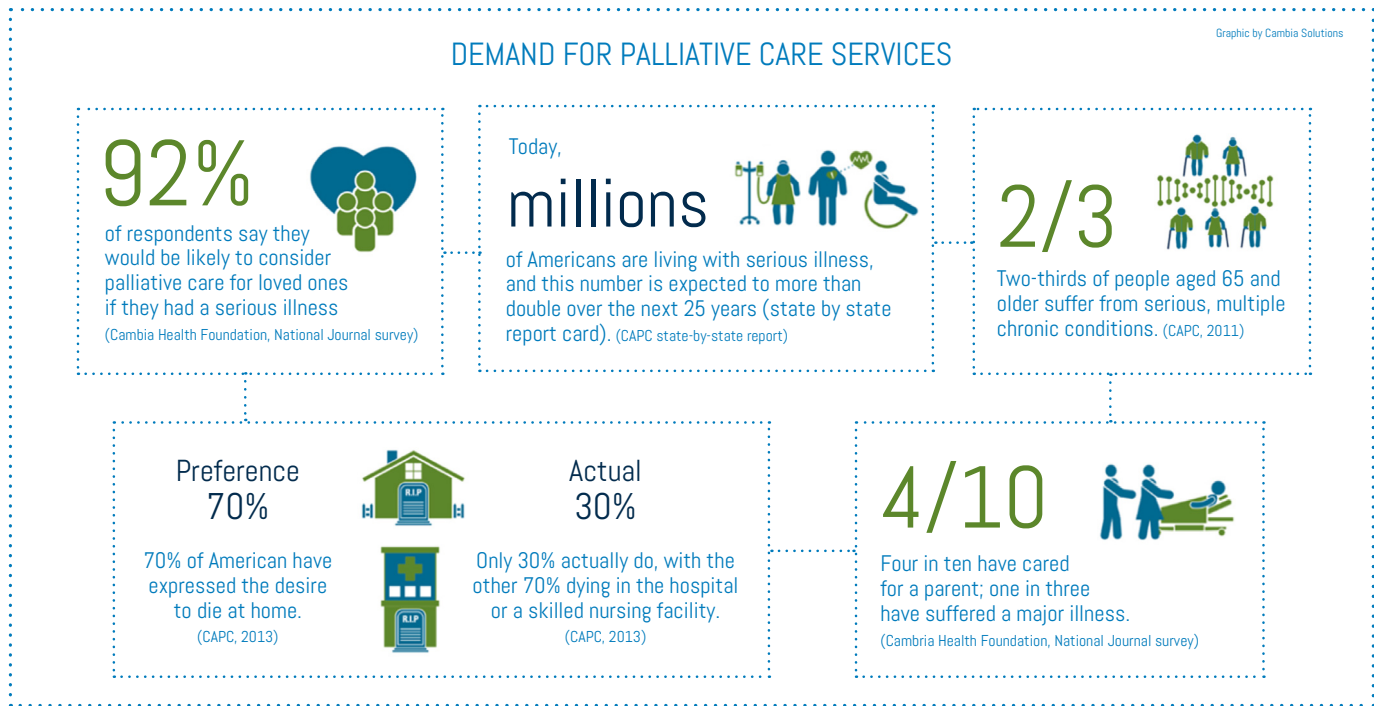
Who is Affected?

Everyone has known or will know someone with a serious illness. Cancer; heart, kidney, liver, and lung diseases; as well as neurodegenerative disease such as dementia, Parkinson's disease, or amyotrophic lateral sclerosis (ALS) are all examples of serious illnesses. Individuals with a serious illness or multiple chronic medical conditions may struggle to perform basic activities of daily living like feeding or bathing themselves, and/or suffer from uncontrolled pain and other symptoms. Individuals living with serious illness can be young or old; they can live for many years after initial diagnosis, or be near the end of life. Although people with serious illness are a diverse group, what they have in common is a high likelihood that they will require extensive care from their families or other caregivers, that they will experience tremendous personal financial burden, and that they may appear repeatedly in hospital emergency departments to address distressing symptoms such as pain and breathlessness. Providing quality care that honors patient preferences is an issue that spans all regions of the country, cultures, and age groups. Though people over 65 use palliative care and end-of-life care more prevalently, the need for improved palliative care and end-of-life care is an issue for children as well.

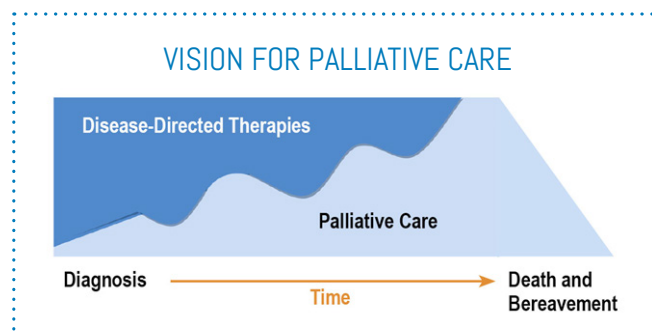
Many Seriously Ill People Have Needs that Are Not Met

Though there are islands of excellent, person-centered care, the current health care system as a whole does not have the support or resources to provide state-of-the-art care for seriously ill patients in the way they need. It does not have an adequate workforce with the knowledge and training to help patients identify their goals and values as they consider treatment options. Not enough clinicians know how to access or provide palliative care or, when appropriate, hospice, to manage their patients' distressing symptoms safely and effectively. It does not have measures to track whether care is patient-centered. There is insufficient research to improve future palliative care and end-of-life care. Finally, the health care system is not equipped to maximize the use of technology to make care information accurate and adequately accessible across care settings.

Too often, these shortcomings result in unnecessary and unwanted care for patients and their families. Approximately 5% of the population is responsible for over 50% of all health care spending.² In many cases, this spending is unnecessary and preventable, and in others, it is for tests, procedures, and treatments that conflict with the person's values and preferences and is therefore unwanted. Expanding access to palliative care and end-of-life care can increase the quality of care for patients and improve the overall sustainability of the health care system.



Part of the problem is the tendency by some providers and some patients to see palliative care as comfort care reserved for people near the end of life, rather than as care integrated into the standard treatment provided to patients facing serious illness. As the box suggests, palliative care can and should be delivered alongside disease-directed (i.e., “curative”) care at the time of diagnosis and throughout treatment and hospice. Research shows that for patients with serious illness greater use of palliative care and hospice improves patients’ quality of life and health outcomes.³ Palliative care and hospice achieve this by matching treatments to patients’ goals, which reduces preventable crises and can lead to cost avoidance to patients, their families and the health care system. Although hospice use has increased, it is commonly used only during the last few weeks or days of life, meaning many patients with serious illness do not get the full benefit of hospice care. Private and public institutions are engaging in promising efforts to improve palliative care and end-of-life care for those with serious illness, and your Departments have an opportunity to build on momentum for this type of person-centered care.



How the New Administration and Congress Can Support Public and Private Sector Innovation

Private sector leaders increasingly recognize the value of palliative care and hospice care, and they have provided important lessons for Medicare. Commercial payers such as Aetna, Regence, Excellus BlueCross BlueShield, and Highmark, Inc. have made advance care planning a priority and are including palliative care offerings for their seriously ill members starting at point of diagnosis and hospice care for those members nearing end of life. States like South Carolina are testing palliative care benefits for their managed care, long-term care, and pediatric populations. Innovative hospitals and health systems participating in alternative payment models are embracing the role these care models can play in improving quality while also improving sustainability. With support from the Administration, we can continue to explore these models in integrated and innovative ways. In addition to what the Administration can do, several bipartisan bills will be introduced in the 115th Congress that, if enacted, will address some of the obstacles and lead to better care for seriously ill Americans. With this goal, leading organizations working with seriously ill patients and their families endorse the following recommendations.

1. Building a Robust Workforce through Education and Training

In order to care for its seriously ill patients, our nation's health care workforce must have the training and skills to deliver palliative care and end-of-life care to a broad diversity of populations. Currently, however, students graduating from medical, nursing and other health professional schools have very little, if any, training in the core precepts of pain and symptom management, advance care planning, communication, cultural competency, and care coordination for this population. As a result, there is a growing gap between the number of seriously ill patients and the number of professionals with the appropriate knowledge and skills to care for them.

This lack of capacity will impact seriously ill patients of all ages, though those 65 and older are the largest and fastest growing population of patients in need of palliative care. Close to half (45 percent) of all Medicare beneficiaries have four or more chronic conditions for which palliative care services may be clinically indicated to alleviate symptoms.⁴ Palliative care in the older population requires accurate identification of all symptoms, and comprehensive geriatric assessments are particularly useful for this purpose.⁵ These geriatric assessments cover complex conditions unique to older adults, and are typically done by an interdisciplinary team of professionals.

Increased palliative care and end-of-life care training is also needed in pediatrics. The American Academy of Pediatrics has called for integration of early pediatric

palliative care as an essential aspect of providing optimal treatment, beginning at the time of diagnosis and continuing along the child's course of care.⁶ Access to pediatric palliative care services varies considerably across the country and must continue to be expanded.

In addition to improved training for care providers focused on particular populations, better training across all care providers will help professionals more accurately determine when seriously ill individuals with cognitive impairment, significant physical or developmental disabilities, or mental illness are in need of palliative care and/or hospice. Such vulnerable patients have been subject to biases resulting in under-treatment, including instances in which symptoms from their chronic health conditions are mistaken as indicators that they are nearing the end of life.

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 serious illness.^{7,8} Federal investment and policies that help build this sector of the workforce are critical to ensuring patients have access to high quality, timely and appropriate care.

1.1 Health Professions and Nursing Education and Training Programs

Narrowing the current and projected health care workforce gap to address the growing number of patients with serious illness will require both an increase in graduating clinicians and training more academic faculty to teach and train future health professionals in palliative care and in geriatrics and gerontology.

- We recommend expanding opportunities for interdisciplinary education and training in palliative care and end-of-life care through new education centers and career incentive awards for physicians, nurses, advanced practice nurses, social workers, and other health professionals, such as proposed in the bipartisan [Palliative Care and Hospice Education and Training Act \(PCHETA\)](#).
- We recommend the Health Resources and Services Administration (HRSA) enhance existing health professions education programs by providing incentives to incorporate palliative care and hospice training, including training focused on care for individuals with cognitive impairment, significant physical or developmental disabilities, or serious mental illness, in education programs for physicians, advanced practice nurses, physician assistants, social workers and other health professionals.
- We recommend the Administration support the bipartisan efforts in Congress to reauthorize nursing workforce programs under Title VIII of the Public Health Service Act (PHSA), and that HRSA's policy objectives include bolstering education in hospice and palliative nursing from primary care to specialty level practice, including programs aimed at pre-licensure through mid-level career

development, in order to meet the growing demands of those with serious illness.

- We recommend the Administration work with Congress to reauthorize and expand resources for the Geriatrics Workforce Enhancement Program (GWEP) under Titles VII and VIII of the PHS Act, and a free-standing, robust Geriatric Academic Career Awards (GACA) program under Title VII to increase the number, frequency and geographic distribution of these awards to include rural and underserved populations and communities.

1.2 Graduate Medical Education (GME)

Under Medicare-financed GME, training in palliative medicine and geriatric competencies should be a priority to ensure better care for those with serious illness. The American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME), which accredits the majority of residency programs, provided formal subspecialty status for Hospice and Palliative Medicine (HPM) in 2006. As such, HPM fellowship programs are not eligible to receive federal funds since Medicare GME funding was capped in 1997. This cap should be updated to address evolutions in medicine and patient needs given the current demographics.

- We recommend increasing the number of residency slots funded by Medicare to align the allocation of new residency slots with identified workforce needs and shortages, including residents in primary specialties who intend to sub-specialize in Hospice and Palliative Medicine or Geriatrics.
- We recommend all appropriate GME programs include palliative care and geriatrics curricula 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.

2. Promoting Measures and Care Models that Improve Quality

2.1 Measuring Quality

For more than two decades, there has been an explosion in the development and use of quality measures in nearly all areas of medicine, with one major exception: palliative care and end-of-life care. While there may be a need to streamline the current array of quality measures, there is broad agreement among hospice and palliative care providers and gerontologists that the U.S. health care system lacks the ability to effectively measure whether people with serious illness are receiving high-quality palliative care and end-of-life care. The current set of measures recently endorsed by the National Quality Forum's (NQF) Palliative and End-of-Life Care

Committee is largely limited to cancer and hospice settings. Furthermore, no measure currently used under federal quality reporting programs or recommended for future years, focuses on the patient population appropriate for palliative care and end-of-life care exclusively.

With the growing emphasis on integrated and value-based care, it is important not only to have appropriate quality measures for palliative care and end-of-life care, but also to have a core set that spans providers, clinicians, care-settings and populations. Such measures must also be created to align new alternative payment models with patient, caregiver, and health system outcomes for quality improvement and accountability. Indeed, the Centers for Medicare and Medicaid Services (CMS), NASEM, and the NQF have all called for measures to evaluate care quality for seriously ill patients across the continuum of care, much as the bipartisan [Improving Medicare Post-Acute Care Transformation Act of 2014 \(IMPACT\)](#) did for the post-acute sector. There also is bipartisan support in Congress for similar patient-centered measures, as demonstrated in the Senate by the [Care Planning Act](#) and in the House by the [Personalize Your Care Act 2.0](#).

- We recommend a portion of the \$75 million appropriated as part of the bipartisan Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) be used to develop measures of quality during serious illness, including a measure set that ensures care provided by physicians reflects a patient’s values, care goals, and treatment preferences over time, and, once tested and proven effective, can be used for accountability and payment decisions.
- We recommend CMS revise patient experience surveys to include the experience of a broader group of patients with serious illness and their families. Patient experience surveys are validated tools that providers use to get the feedback necessary for patient-centered care. Unfortunately, current consumer data collection systematically excludes input from, and data important to, the seriously ill population. CMS should revise the Consumer Assessment of Healthcare Providers and System program (CAHPS) and other appropriate surveys to:
 - Use proxy reporting (i.e., family members and care providers in the case of patients who die) as modeled by hospice and home health CAHPS;
 - Require providers to survey patients who transition to another setting of care; and
 - Expand surveys to capture information beyond the physical aspects of care that is crucial to seriously ill patients.
- We recommend the President direct the Secretary of Health and Human Services (HHS) to develop patient-centered measures that take into account patient goals, preferences and values and the agreement of care plans with outcomes.

- We recommend harnessing the Beneficiary and Family Centered Care Quality Improvement Organizations' expertise to improve the collection and honoring of patient preferences.

2.2 Expanding Innovative Models of Care

Innovative payment and care models provide opportunities to test new ways to deliver and pay for care, helping policymakers distinguish between those interventions that work and those that may not. CMS has funded a number of groundbreaking models that support the delivery of acute care services but far fewer to individuals with serious illness. There is a need to test additional models that address the care of Medicare beneficiaries with multiple, chronic conditions throughout the care continuum. We encourage the Administration and Congress to direct CMS to adopt and evaluate these models, and disseminate the findings for wider implementation.

- We recommend CMS extend and improve innovative models of care that expand use of palliative care and help address issues seriously ill patients face at the end of life. As it selects and pilots new care models, we recommend CMS:
 - Include palliative care and end-of-life care as components of new models and demonstration projects for delivery design, quality measurements and payment;
 - Be transparent and consistent about how supported models are evaluated to allow for broader dissemination and replication of models and outcomes measurements;
 - Provide technical assistance to those entities seeking to adopt and scale successful models once identified and evaluated;
 - Increase patient access to advance care planning services, particularly in rural areas and low-income communities, as well as those populations chronically under-served;
 - Incorporate a wide variety of settings and diversity of participants to address individual differences and barriers to implementation and dissemination; and
 - Allow for home-based support for seriously ill patients.
- We recommend refining and expanding existing demonstrations, such as the Medicare Care Choices Model, and testing new care models that offer concurrent hospice and disease-directed care, expand access to palliative care, increase access to advance care planning and improve patient-centered care for individuals with serious illness. These policy changes could include efforts to:
 - Explore policy options to increase the number of hospice consultations and referrals for those with serious illness or a change in health status;

- Expand hospice eligibility to individuals earlier in their disease trajectory; and
- Enhance care coordination and improve transitions from primary and specialty care to hospice, including transitions for those no longer eligible for hospice services.
- We recommend adopting models of public-private partnership that increase access to palliative care and hospice for veterans. The Veterans Health Administration (VHA) has long been a leader in providing high-quality palliative care and hospice services. The VHA has also been critical in addressing the needs of rural veterans with serious illness through its rural partnerships with academic medical centers. As the population of veterans needing these services continues to grow, we must ensure there are medical, nursing, and other health professionals able to care for them by:
 - Increasing the number of inter-professional palliative care fellowship programs to include more sites across the country, and increasing the number of slots in those programs;
 - Strengthening training opportunities in palliative care and hospice through the U.S. Department of Veterans Affairs (VA); and
 - Adopting more broadly the VA allowance of concurrent disease-directed therapy and hospice care as a model for payment programs across all beneficiaries.

3. Supporting Research to Strengthen Palliative Care and End-of-Life Care Practice

To provide effective and compassionate care for this vulnerable group of Americans, their families, and caregivers, it is imperative that care for seriously ill patients is supported by data from high-quality studies conducted specifically with this diverse population. Unfortunately, unlike other areas of medicine, the knowledge base to support the basic elements of palliative care and end-of-life care (i.e., pain and symptom management, communication skills, care coordination) is relatively small, as is the research community dedicated to the biomedical, cultural competence, and clinical and behavioral needs of this field. Part of the problem is the minimal funding dedicated to support such research. Less than one percent of all grants funded by the National Cancer Institute; National Heart, Lung and Blood Institute; National Institute on Diabetes, Digestive and Kidney Diseases; National Institute on Nursing Research; and the National Institute on Aging were awarded to investigators performing palliative care research.⁹ Yet, the leading serious medical illnesses in this country

are cancer, dementia, and diseases of the heart, lung, and kidney — all conditions associated with high degrees of suffering, preventable hospitalizations, high family and caregiver burden, and all of which are aided by palliative care. Multiple reports have noted the need to develop research networks and multi-site studies to establish a knowledge base that contributes to the goal of bringing an evidence-based approach to palliative care and end-of-life care.¹⁰

- We recommend enhancing federal research throughout the continuum of care for patients with serious illness as embodied in the PCHETA legislation. The National Institutes of Health (NIH) can accomplish this by:
 - Developing and implementing a strategy applied across all NIH institutes and centers to expand national research programs in palliative care;
 - Expanding and intensifying NIH research programs in palliative care to strengthen clinical practice and health care delivery and yield meaningful evidence to improve the quality of care and quality of life for the rapidly growing and diverse population of Americans with serious or life-threatening illnesses;
 - Conducting prospective intervention trials and epidemiological studies to better understand how advance care plans, including Physician Orders for Life Sustaining Treatment (POLST) forms, change clinical outcomes and health care utilization; and
 - Expanding trans-NIH research reporting to include palliative care research.

4. Improving Health Information Technology to Honor Patients' Preferences

It is essential that everyone involved in health care delivery understands and respects patients' values, goals of care and treatment preferences. Advance care plans are critical tools for ensuring that people with a serious illness are able to get the care they prefer. A medical crisis can quickly transform a previously healthy person into someone who is unable to make his or her own health care decisions. Creating an advance care plan by eliciting, capturing, and tracking patients' preferences helps ensure they maintain control over the care they receive, particularly when they are no longer able to speak for themselves. The chart below describes the various types of advance care plans.

Advance care planning includes having conversations with patients and their families about values, care goals, and treatment preferences, and completing the appropriate forms to document this information. Unfortunately, most electronic health records (EHRs) do not alert clinicians to the presence of these documents, and they often go

unnoticed in the growing streams of data within the health record. This is particularly troublesome as many critical decisions made by clinicians, especially in urgent settings or when patients are not able to communicate, are dependent upon guidance found in advance care plans. One published quality improvement effort found advance care plans were documented in seven different locations within an EHR,¹¹ while another study found that clinicians needed more than 12 steps or an average of 4.3 minutes to locate an advance care plan.¹² As multiple layers of patient-generated data are added to EHRs over time, it will only become harder to find a patient’s advance care plan — with serious implications for patient choice and quality of care. Since an advance care plan articulates how a patient would like to be cared for, it should be “front and center” in his or her health record. Like information about allergies and blood type, these documents, especially medical orders like POLST Forms, should be available in a single-click.

ADVANCE CARE PLANS are all documents related to advance care planning: legal documents; medical orders; and notes from conversations between individuals and their health care professionals. Without these, patients receive our current standard of care, which is to do everything possible in an attempt to save the patient’s life.

	Legal Documents	Medical Orders
Includes	<ul style="list-style-type: none"> • advance directives • living wills • health care power of attorney 	<ul style="list-style-type: none"> • Do No Resuscitate (DNR) Orders • POLST Forms. Name varies by state.
Purpose	<ul style="list-style-type: none"> • Identify a surrogate decision-maker. • Provide general wishes about treatments. 	Provides specific medical orders for an expected medical emergency.
Who Needs	All competent adults.	Seriously ill and frail patients that health care providers would not be surprised if they died within a year.
Use During a Medical Crisis	No. These are used to develop care plans once patient is stabilized.	Yes.

- We recommend the Office of the National Coordinator for Health Information Technology (ONC) be directed to create a certified health electronic record technology (CEHRT) standard that requires an immediately-accessible link to any advance care planning document within an electronic health record.

Access to a patient’s most recent treatment preferences becomes more difficult when a patient transfers from one care setting to another, as advance care plans are often not included in the transfer documentation. This disruption in the continuity of care for medically vulnerable individuals can result in unwanted, unnecessary and preventable treatment. One study found the likelihood that the information in a patient’s advance care plan was available in a new setting was “no greater than chance.”¹³ This difficulty in locating a patient’s advance care plan is especially problematic since, on average, a person experiences three transitions in care settings during his or her final three months of life.¹⁴

Maintaining access to those up-to-date advance care plans as patients are transferred across care settings is a more complex issue, requiring strong care transition protocols and effective interoperability across systems — issues that clearly transcend the fields of palliative care and end-of-life care. Recent bipartisan passage of the [21st Century Cures Act](#) begins the process of increased interoperability and decreased information blocking. As specifics become available regarding which components of care delivery are prioritized in information-sharing initiatives, we welcome the opportunity to participate in problem solving to improve care and support honoring patients’ goals of care.

Contact Information for Participating Organizations

American Academy of Hospice and Palliative Medicine

Jacqueline M. Kocinski, MPP
Director, Health Policy and Government Relations
American Academy of Hospice and Palliative Medicine
jkocinski@aahpm.org
847.375.4841

American Cancer Society Cancer Action Network

Keysha Brooks-Coley
Senior Director, Advocacy Strategic Alliances
keysha.brooks-coley@cancer.org
202.661.5720

American Geriatrics Society

Nancy E. Lundebjerg, MPA
Chief Executive Officer
nlundebjerg@americangeriatrics.org
212.308.1414

American Heart Association/American Stroke Association

Mark Schoeberl
Executive Vice President, Advocacy and Health Quality
mark.schoeberl@heart.org
214.706.1299

Blue Shield of California

Torrie Fields, MPH
Senior Program Manager, Palliative Care
Healthcare Quality & Affordability
Torrie.Fields@blueshieldca.com
415.229.5839

Cambia Health Solutions

Peggy Maguire
Senior Vice President, Corporate Accountability & Performance
margaret.maguire@regence.com
503.226.8706

Center to Advance Palliative Care

Diane E. Meier, MD, FACP, FAAHPM
Director
c/o: Stacie.sinclair@mssm.edu
212.201.2670

Coalition to Transform Advanced Care

Marian Grant, DNP, ACNP-BC, ACHPN, FPCN, RN
Director of Policy and Professional Engagement
mgrant@thectac.org
443.742.8872

Consumer Coalition for Quality Health Care

Brian W. Lindberg
Executive Director
brian@consumers.org
202.789.3606

National Coalition for Hospice and Palliative Care

Amy Melnick, MPA
Executive Director
amym@nationalcoalitionhpc.org
202.306.3590

National Hospice and Palliative Care Organization

Jonathan Keyserling
Senior Vice President, Office of Health Policy
jkeyserling@nhpco.org
703.837.1500

National Partnership for Hospice Innovation

Marian Grant, DNP, ACNP-BC, ACHPN, FPCN, RN
Director of Policy and Professional Engagement
mgrant@thectac.org
443.742.8872

National POLST Paradigm

Amy Vandenbroucke, JD
Executive Director
amy@polst.org
202.780.5738

The Pew Charitable Trusts

Lee Goldberg, JD
Director, Improving End-of-Life Care Project
lgoldberg@pewtrusts.org
202.552.2127

END NOTES

1. U.S. Department of Health and Human Services, Administration for Community Living (September 2014). "Administration on Aging (AoA) Projected Future Growth of Older Population." Administration on Aging, Administration for Community Living, www.aoa.acl.gov. https://aoa.acl.gov/Aging_Statistics/future_growth/future_growth.aspx.
2. Cohen, S. and Yu, W. (January 2012) "The Concentration and Persistence in the Level of Health Expenditures over Time: Estimates for the U.S. Population, 2008–2009." Statistical Brief #354. Agency for Healthcare Research and Quality, Rockville, MD. http://www.meps.ahrq.gov/mepsweb/data_files/publications/st354/stat354.shtml
3. Kavalieratos D, et al. (2016). "Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis." *Journal of the American Medical Association* 316 (20):2104-2114. doi:10.1001/jama.2016.16840.
4. Kaiser Family Foundation (March 2015). "A Primer on Medicare: Key Facts About the Medicare Program and the People it Covers."
5. O'Neill, L.B. and Morrison, R.S. (May 2015). "Palliative care: Issues specific to geriatric patients." UpToDate.
6. Committee on Bioethics and Committee on Hospital Care (August 2000). "Pediatrics Palliative Care for Children." *American Academy of Pediatrics* 106 (2) 351-357. <http://pediatrics.aappublications.org/content/106/2/351>.
7. Institute of Medicine (2015) "Dying in America: Improving quality and honoring individual preferences near the end of life." The National Academies Press, Washington, DC.
8. MedPAC report to the Congress: Aligning Incentives in Medicare, June 2010, p. 111, https://www.aacom.org/docs/default-source/grad-medical-education/jun10_entirereport.pdf?sfvrsn=2.
9. Morrison, R. S. (2014). Ch. 15 in "Meeting the Needs of Older Adults with Serious Illness" Eds. Amy S. Kelley, Diane E. Meier; Source article: Gelfman LP, Du Q, Morrison RS (2013). "An update: NIH research funding for palliative medicine from 2006 to 2010."
10. Building Momentum: The Science of End-of-Life and Palliative Care. A Review of Research Trends and Funding, 1997-2010. The National Institutes of Health, the National Institute of Nursing Research (2013).
11. Loguidice, C., (July 2014). "Improving Accessibility to Advance Directives in Electronic Health Records," *Annals of Long-Term Care*, <http://www.annalsoflongtermcare.com/news/ags-2014-advance-directives-electronic-health-records>.
12. Yung, V. Y., et al., (2010). "Documentation of Advance Care Planning for Community-Dwelling Elders," *Journal of Palliative Medicine* 13(7): 861–67.
13. Yung, V. Y., et al., (2010). "Documentation of Advance Care Planning for Community-Dwelling Elders." *Journal of Palliative Medicine* 13(7): 861–67, Cit. loc: (p865).
14. Teno, J. M., Gozalo, P. L., Bynum J. P. W., et al. (2013) "Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009." *Journal of the American Medical Association*. 309 (5):470-477. doi:10.1001/jama.2012.207624.