

**The
Coalition to
Transform
Advanced
Care
(C-TAC)**

**Policy Agenda:
*Options to Transform
Advanced Care***

[April 2015]

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Introduction

Since its launch in 2011, the Coalition to Transform Advanced Care (C-TAC) has convened leaders, experts, policymakers, and stakeholders in the field of advanced illness. Advanced illness is defined as when one or more conditions become serious enough that general health and functioning decline and treatment begins to lose effect – a process that extends to the end of life. Individuals with advanced illness have one or more chronic conditions, but their decline in health and function is more pronounced, faster, and in many cases irreversible. In short, a person with advanced illness has entered the “gray zone” between treatable and terminal illness. This may happen in the course of any disease and at any age but is more common in older populations. When facing advanced illness, many individuals fall through the cracks between current programs and providers. Most are not yet eligible for hospice and many who do qualify are reluctant to enroll or their physicians are unwilling to refer them.¹

Comprehensive, high quality advanced illness care includes a broad range of clinical services, including palliative care and hospice care, but is not synonymous with either and nor is it end-of-life care only. Innovations in advanced illness care are demonstrating that a coordinated, person-centered approach yields better care, greater satisfaction and, as a side benefit, lower costs.² Building and scaling best practice models for advanced care management is key to driving system-wide change on the federal, state, and local levels.

C-TAC is striving for change in the health care system and larger environment by disseminating best practices and proven solutions in advanced care delivery, promoting professional education, supporting policy and advocacy, and building public demand and empowerment for quality advanced care. Our mission is to transform advanced illness care by empowering consumers, changing the health delivery system, improving public and private policies, and enhancing provider capacity.

This policy agenda has been developed in collaboration with C-TAC’s membership. It reflects areas of consensus for federal and state policymakers and private stakeholders to act on to improve care for individuals with advanced illness and their families. The options in this book are guided by four core principles:

¹ Vig, E., Starks, H., Taylor, J. et al. 2010. “Why don’t people enroll in hospice? Can we do anything about it?” *Journal of General Internal Medicine*. 25, 10, 1009-1019.

² Institute of Medicine. 2014. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. National Academies Press: Washington DC.

- 1. Transform advanced care via movement to value-based payment and quality measure development.**
- 2. Align treatment and care objectives with patient goals, values, and preferences across time, setting, and medical condition.**
- 3. Engage individuals with advanced illness, their families, and caregivers with a full range of supports and services.**
- 4. Strengthen professional education and engagement in collaborative, team-based models of person- and family- centered care delivery.**

There is a growing awareness of the need to transform advanced care in the U.S. and more opportunities are arising to do so. First, the Institute of Medicine (IOM) recently released a report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*,³ which made a number of recommendations on how to improve care for Americans nearing the end of life. Second, there are broad transformations in the healthcare system underway that offer opportunities to speed the adoption of effective advanced care programs. Specifically, the movement to pay providers for the value of care they deliver – and not just the volume of services – has accelerated greatly over the last few years. In this context, caring and supporting those with an advanced illness is an important part of the care management puzzle for providers aiming to deliver high value care that both improves quality and reduces costs. The alignment between broader healthcare system trends and C-TAC’s mission has created a unique environment to significantly expand and improve care for those with advanced illness, drive health system transformation, and promote long term sustainability of the system.

Supporting the Advanced Care Model

Shifting U.S. demographics, coupled with a lack of access to evidence-based advanced care models, will place increasing pressure on those with advanced illness and their families. In 2000, 12.4 percent of Americans were 65 years or older, but this number is projected to reach 20.6 percent by 2050.⁴ The vast majority of people with advanced illness will be in this age group, though advanced illness can occur from birth to old age. As our nation ages, experts predict that the number of new cases of disease that are intensive to treat and care for will also increase, such as cancer and Alzheimer’s disease.⁵ For instance, over

³ Ibid.

⁴ He, W., Sengupta, M., Velkoff, V. et al. 2005. “65+ in the United States.” Accessed October 7, 2014. <http://www.census.gov/prod/2006pubs/p23-209.pdf>

⁵ Institute of Medicine. 2014. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. National Academies Press: Washington DC.

one-third of Medicare beneficiaries have 4 or more chronic conditions. Many of these individuals will eventually require long term care.⁶

Along with these statistics, there is ample evidence that individuals with advanced illness and their families do not have access to high-quality, person- and family- centered care. A recent Health and Human Services (HHS) initiative directed at the one in four Americans that are affected by two or more chronic diseases, indicated that these individuals are at greater risk for unnecessary hospitalizations, adverse drug reactions and conflicting medical advice that may be overwhelming to patients and families.⁷ Too often, these individuals and their family caregivers are provided little guidance to make informed decisions about their care. Families and caregivers devote incredible amounts of time to the care of their loved ones in the last year of life – an average of nearly 66 hours per week.⁸ Discussions about end of life planning are often delayed until treatment options are exhausted.⁹ Often, family caregivers believe they have no other option than to call 911 for transport to the Emergency Department and admission to the hospital.¹⁰ Once admitted, transfer to the ICU without their informed consent is routine.¹¹ Palliative care and hospice are often considered last resorts, despite the fact that, ironically, both extend survival compared to “usual care.”^{12,13}

This lack of access to quality care can extend into end of life. A California Healthcare Foundation (CHCF) survey found that approximately 70 percent of respondents stated a preference to die at home; however, only 32 percent experienced death at home, while 42 and 18 percent died in hospitals and nursing homes, respectively.¹⁴ Other studies have documented similar trends, with one finding a concordance rate of only 37 percent between preferred and actual site of death.¹⁵ These statistics underscore the need to reform the way advanced illness care is provided in the U.S.

⁶ Centers for Medicare and Medicaid Services. 2012. “Chronic Conditions Among Medicare Beneficiaries.” Accessed October 7, 2014. <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Downloads/2012Chartbook.pdf>

⁷ U.S. Department of Health and Human Services. 2010. Multiple Chronic Conditions—A Strategic Framework: Optimum Health and Quality of Life for Individuals with Multiple Chronic Conditions. http://www.hhs.gov/ash/initiatives/mcc/mcc_framework.pdf

⁸ Rhee, Y, Degenholtz, H., LoSasso, A. et al. 2009. “Estimating the quantity and economic value of family caregiving for community-dwelling older persons in the last year of life,” *Journal of the American Geriatrics Society*, 57, 1654-1659.

⁹ Keating N., Landrum, M., Rogers, S. et al. 2010. “Physician factors associated with discussions about end-of-life care.” *Cancer*, 116, 998-1006.

¹⁰ Smith, A., McCarthy E., Weber E., et al. 2012. “Half of older Americans seen in emergency department in last month of life; most admitted to hospital, and many die there.” *Health Affairs*, 31, 6, 1277-1285.

¹¹ Rady M. & Johnson D. 2004. “Admission to intensive care unit at end-of-life: is it an informed decision?” *Palliative Medicine*, 18, 8, 705-711.

¹² Temel J., Greer J., Muzikansky A. et al. 2010. “Early palliative care for patients with metastatic non-small-cell lung cancer.” *New England Journal of Medicine*, 363, 8, 733-742.

¹³ Connor S., Pyenson B, Fitch K, et al. 2007. “Comparing hospice and non-hospice patient survival among patients who die within a 3-year window.” *Journal of Pain Symptom Management*, 33, 3, 238-246.

¹⁴ California Healthcare Foundation. 2012. “Final Chapter: Californians' Attitudes and Experiences with Death and Dying,” Accessed October 7, 2014. <http://www.chcf.org/publications/2012/02/final-chapter-death-dying#ixzz3FTXnjduE>

¹⁵ Fischer, S., Min, S., Cervantes, L. et al. 2013. “Where Do You Want to Spend Your Last Days of Life? Low Concordance Between Preferred and Actual Site of Death Among Hospitalized Adults.” *Journal of Hospital Medicine*, 8, 4, 178-183.

Advanced care provides this new transitional pathway from curative to comfort care and fills a void in the continuum of clinical services available to persons with advanced illness:

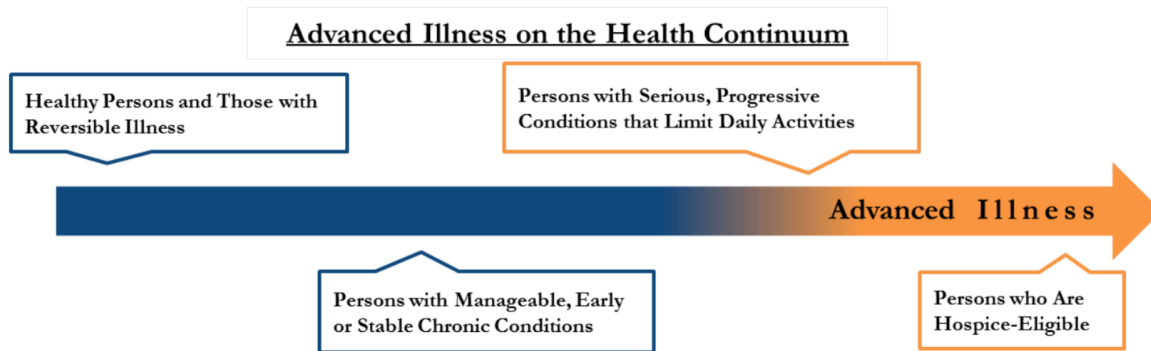


Figure 1. Complex care management provides intensive medical management to patients who are expected to recover. Advanced care provides comprehensive care management to people who have poor prospects for full recovery. Hospice provides care management for patients who are terminal. Palliative care provides symptom management and support at any stage of illness.

Advanced care offers comprehensive services available across settings and time, and combines active treatment with palliative care, customized to match personal values and preferences as they evolve through the process of illness and adaptation. Palliative care is a key component of this overall approach to care management. As defined by the 2014 Institute of Medicine (IOM) report, *Dying in America*, palliative care can be defined as: “Care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. Palliative care may begin early in the course of treatment for a serious illness and may be delivered in a number of ways across the continuum of health care settings, including in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics. Palliative care encompasses hospice and specialty palliative care, as well as basic palliative care.”¹⁶

The advanced care model actively integrates settings of care delivery that are now disconnected, such as hospitals, primary care offices and clinics, specialists, nursing homes, and home and community settings. It also re-engineers care delivery by leveraging the capabilities of current service components like inpatient and office-based case management, palliative care, caregiver support, nursing homes, home health, and hospice. Through repurposing and retraining, new care teams can increase clinical effectiveness, promote patient choice and reduce operational costs by avoiding unwanted hospital admissions and eliminating unnecessary services, tests and procedures.

¹⁶ IOM (Institute of Medicine). 2014. *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.

Barriers to Care Delivery

In developing this policy agenda, C-TAC has outlined key barriers to the delivery of high-quality advanced care. Clinical, social, and cultural barriers reinforce the uncoordinated and unsupportive care currently delivered to individuals with advanced illness and their families. The goal of the policy options presented is to address these barriers, clearing the way for the building, replication, and improvement of advanced care programs. The most significant barriers can be classified across five categories:

- 1. Lack of Person-Centered Care Coordination in Advanced Illness** – Often, care delivery is fragmented and uncoordinated, with patients treated across providers and settings without sufficient communication about their treatment or coordination among involved health professionals. Individuals with advanced illness are left to navigate the system with little support for their financial, emotional, spiritual, and social needs or discussion and support for the choices that should be made. Care delivery depends on which benefits they have through Medicare or another payer, which providers are permitted to offer those services, and which services are available in a given community – and not the personal goals and preferences of individuals, families, and caregivers. There is also a lack of comprehensive quality metrics that can properly assess the quality of care delivery and the patient and family caregiver experience.
- 2. Lack of Widely Accepted Standards of Care** – The adoption and implementation of widely accepted standards of care for advanced illness are still evolving within the professional community and are necessary for a systemic approach to advanced illness standards of care delivery. Areas for development include: 1) prompt identification of individuals with advanced illness and their family caregivers, 2) counseling and discussion of individual values, goals, preferences, and treatment options at time of initial diagnoses and during the treatment process, 3) respect for individual choices that tailors treatment plans to values, goals, and preferences, 4) timely and appropriate use of advanced care services, and 5) support, relief of pain and other distressing symptoms, and counseling appropriate to circumstances.
- 3. Payment Barriers** – FFS payment models with misaligned incentives impede care coordination across providers and settings – and high-quality and high value care as a result. Burdensome regulations and statutory provisions can prevent providers and interdisciplinary teams from optimizing workplace efficiencies and may limit payments to family caregivers. All of these factors create an opportunity to improve access and quality without increasing cost. Fortunately, these goals and preferences can be achieved by adding choices for individuals and their families, not restricting services.
- 4. Need for Public Engagement** – For a range of reasons, individuals with advanced illness, and their families and caregivers often do not have advance care plans nor have they discussed future plans of care with a team of providers. They often lack access to proper advance care planning tools or

are unaware of the resources already available to them in their communities. Compounding this problem, providers are often unaware or do not engage in discussions regarding treatment and support options until later on – or too late – in the course of illness. Lastly, care plans are often poorly documented or difficult to retrieve in electronic medical records. Many states also have burdensome laws and regulations in regards to the transferability and portability of directives across state lines.

- 5. Limited Caregiver Resources** – Families and caregivers often lack comprehensive financial, emotional, spiritual services to support themselves while providing for their loved ones. They may also be unaware of available information and resources to help guide them through the care process.
- 6. Workforce Limitations** – The existing healthcare workforce requires additional support and preparation to appropriately care for the growing number of Americans with advanced illness. Constraints in the needed number and distribution of nurses, primary care physicians, direct care workers, social workers, and spiritual advisors in the health care setting may prevent individuals from receiving the care they want. Many care professionals may need additional training to provide caregiving and supportive services (e.g. medication management and care planning and transitions) to those with advanced illness.

Below are a series of policy options designed to address these barriers and support the four core principles outlined above. The policy options outlined below can be accomplished through different advocacy avenues including public and private partnerships in many cases. While some policy changes may require Congressional action, many can be accomplished via regulation and at the state level. In particular, states are leading many of the innovative changes in healthcare today through Medicaid programs, State Innovation Model (SIM) grants, and other state-led demonstrations. Federal actors, states, and private entities are essential to transform care delivery for individuals with advanced illness – and the policy options in this document aim to leverage all of these stakeholders to drive meaningful change.

I. Transform advanced care via movement to value-based payment and quality measure development

The current fragmented and uncoordinated care individuals with advanced illness often receive is driven by a fee-for-service (FFS) payment system with misaligned incentives that rewards volume over value. The current system is also outdated in terms of what services are reimbursed and when individuals are eligible for certain services and benefits. For instance, to qualify for hospice, Medicare requires a beneficiary to be certified as likely to die in 6 months, and forego “curative” treatment, a standard which is outdated and counter-productive to providing person-centered care.

However, the movement to transition the current health care payment system to one that is value-based is underway. In this new payment paradigm, providers are rewarded for improving quality, improving health outcomes, and reducing costs. New payment and delivery reform programs, demonstrations, and pilots are being tested and implemented across the country with both public and private payers. The goals of comprehensive advanced care management are in line with the new payment paradigm that aims to drive greater value in the healthcare system. Unfortunately, few public payer models are focusing on advanced illness care that is provided upstream – before a crisis occurs. Supporting its inclusion in patient-centered medical home (PCMH), bundling, accountable care organization (ACO), and global payment initiatives is critical to transformation of advanced care, as well as overall system transformation.

Barrier	Policy Objective	Solution	Advocacy Actors
<p>Lack of industry-wide standards for advanced illness management and narrowly defined payment structures impede the adoption of high quality, well-coordinated, and person-centered models of care delivery</p>	<p>Promote advanced care management through payment and delivery reforms</p>	<ul style="list-style-type: none"> ▪ Build on existing federal and state demonstrations and programs to replicate and scale effective advanced care programs. States and HHS should make scaling and replicating effective advanced care programs a priority. For instance, CMMI could work with State Innovation Model (SIM) grantees, as these grants offer opportunities to change care delivery across payers. In addition, Innovation Accelerator Program (IAP) funds could be used to assist states with implementing advanced care programs. Last, the Money Follows the Person demonstration has successfully moved individuals away from institutional care and could include the option 	<ul style="list-style-type: none"> ✓ HHS/CMMI ✓ States

		<p>to offer effective advanced care programs.</p> <ul style="list-style-type: none"> ▪ Increase funding for demonstrations to examine strategies to improve coordination of care across time, care settings, and diagnoses, and provide funding to scale successful innovations nationally. CMMI should fund demonstrations in order to test innovative strategies and approaches to caring for this population. ▪ Provide incentives for Medicaid programs to increase establishment and use of advanced care programs. CMS should pilot incentives for state Medicaid FFS and managed care programs to adopt advanced care programs. Congress could provide incentives for FFS and managed care to adopt evidence-based advanced care models (e.g. increase in FMAP modeled after the increase for covering preventive services with \$0 dollar cost sharing, or requiring managed care organizations to do so as part of Medicaid 	<p>✓ HHS/CMMI</p> <p>✓ Congress ✓ HHS/CMMI ✓ States</p>
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		<p>contracts).</p> <ul style="list-style-type: none"> ▪ Create transition payments to facilitate development and adoption of advanced care programs. Provide initial pay-for-performance payment for advanced care management services across the continuum of healthcare settings that meet defined quality metrics. Transition the pay-for-performance payment system to models with shared risk as advanced care clinical models evolve and as broader value-based payments replace fee-for-service. Incorporate advanced care measures into the Medicare Advantage (MA) Stars rating system to incent the provisions of advance care planning – including measures on access to advance care planning services, completion of advance directives, advanced illness care quality, and person- and family-centeredness. ▪ Include incentives or requirements for providers to establish or deliver advanced care programs through Medicare value-based payment programs. CMS should 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ NQF ✓ Congress ✓ HHS/CMS ✓ States
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		<p>promote the adoption of advanced care programs via Medicare payment and delivery reforms, including the Medicare Shared Savings Program (MSSP), Bundled Payment Care Initiative (BPCI), Patient-centered Medical Homes (PCMHs), and others where appropriate. These new funding models provide financial incentives for providers and payers to more effectively manage advanced illness and build functional and staff capacities.</p>	
<p>Lack of comprehensive quality metrics to properly assess care delivery and reward value rather than volume-based care</p>	<p>Enhance quality measure development</p>	<ul style="list-style-type: none"> ▪ Develop and gather consensus around comprehensive quality metrics (process, outcomes and patient/family experience) to assess the quality of care delivery through public-private relationships. Metrics should assess whether treatment was concordant with individual and family goals and preferences and the quality of the advance care planning discussions. CMS and private plans should build on existing 14 evidence-based quality measures or domains endorsed by NQF for palliative and EOL care. 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ NQF ✓ Private Stakeholders

		<ul style="list-style-type: none"> ▪ Create and develop consensus around metrics for appropriate and timely referral to hospice in Medicare. The feasibility of clinical standards for timelier referral to hospice care should be studied, and as appropriate, developed, and implemented. ▪ Create and develop consensus around standard metrics appropriate for persons with advanced illness. Creating metrics specific to those with chronic disabling conditions will support the longitudinal provision of services to maintain function or to slow decline, rather than requiring improvement for services to continue. ▪ Encourage public reporting of palliative, end of life, and advanced care quality measures through Federal health programs. Collecting and reporting data on advanced care through all Federal health programs will provide a comprehensive understanding of current state of care, focus providers on improving advanced care, and allow for a transition to value-based payment for advanced care. This should also track progress on improving advanced care and measure its impacts. 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ NQF ✓ Private Stakeholders ✓ Congress ✓ HHS/CMS ✓ NQF ✓ Private Stakeholders ✓ Professional Associations ✓ Congress ✓ HHS/CMS ✓ States ✓ Professional Associations
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<p>Regulatory and administrative barriers to adopting and implementing effective advanced care programs</p>	<p>Utilize research and quality measure development to facilitate inclusion of advanced care in new payment models</p>	<ul style="list-style-type: none"> ▪ Develop requirements, standards, and procedures for accreditation of hospital- and community-based palliative care programs. Standardized accreditation will help accelerate palliative care quality improvement initiatives throughout the acute and post-acute service areas. Increase palliative care integration into care models. ▪ Revise criteria for hospice eligibility in Medicare, and examine access to hospice for Medicaid beneficiaries. Criteria should take into account current evidence on the role and effectiveness of hospice care for individuals with advanced illness. Hospice care is currently an optional service for state Medicaid programs, which should be examined to determine whether access to the full continuum of advanced care and hospice services for those with serious illness is impeded as a result. ▪ Amend payment rules for telehealth. Current payment rules for telehealth, and regulatory barriers have impeded the widespread use of these services. However, telehealth use in advanced 	<ul style="list-style-type: none"> ✓ HHS/CMS ✓ Private stakeholders (NQF, JCAHO) ✓ Congress ✓ HHS/CMS ✓ Congress ✓ HHS/CMS ✓ States
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		<p>care programs could promote care coordination across homes, acute and PAC, and outpatient settings. Payment should be provided for services that meet criteria for care coordination for advanced care.</p>	
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II. Align treatment and care objectives with patient goals, values, and preferences across time, setting, and medical condition

Individuals with advanced illness and their families should be engaged in an ongoing care planning process. Advance care planning is a dynamic process that occurs over the course of an illness, and involves understanding, reflecting on, and discussing future medical decisions, including end of life preferences.¹⁷ Promoting public knowledge, especially among those with chronic illness and Medicare beneficiaries, on the full array of advance care planning processes and tools will help prompt ongoing discussions between individuals and an interdisciplinary team of providers. These discussions are necessary for both articulating care goals and preferences and for successfully capturing those plans in a format that can be shared and updated. A 2012 survey found that 42 percent of respondents had discussions about end of life issues, but only about half – 21 percent – had put any care directives in writing.¹⁸ Also telling, while 77 percent of respondents said they would “probably” or “definitely” want to discuss treatment at the end of life with their physician, 90 percent said their physician had never asked them about the issue.¹⁹

In particular, improving knowledge and addressing literacy on advanced illness issues among targeted groups is critical. A study of approximately 800 patients from 55 to 74 years of age found that half of those with adequate levels of health literacy, approximately 25 percent with marginal literacy, and 12 percent of those with low literacy reported they had advance directives.²⁰ People generally have little awareness or understanding of advanced illness topics—for instance, 78% do not know what palliative care is. The problem is compounded when similar words are interpreted differently. In surveys of adults over age 25, “serious illness” connotes terminal illness to 18%, while “advanced illness” signifies terminal illness to

¹⁷ Honoring Choices Wisconsin. 2014. “Glossary and Style Guide.”

¹⁸ California Healthcare Foundation. 2012. “Final Chapter: Californians’ Attitudes and Experiences with Death and Dying,” Accessed October 7, 2014. <http://www.chcf.org/publications/2012/02/final-chapter-death-dying#ixzz3FTXnjduE>

¹⁹Ibid.

²⁰ Waite, K., Federman, D., McCarthy, R. et al. 2013. Literacy and race as risk factors for low rates of advance directives in older adults. *Journal of the American Geriatrics Society*, 61, 3, 403-406.

36%.²¹ Another study found less than one in five have heard the terms palliative care (17%) and POLST (Physicians Orders for Life Sustaining Treatment) (13%); however, hospice (73%) and do-not-resuscitate (DNR) orders (63%) are more familiar terms.²² However, research has shown that effective communication among providers, patients and their families can improve medical outcomes, increase patient and family satisfaction and reduce burden on the health care system.^{23,24,25,26,27} Empowering individuals with advanced illness and their families with knowledge on relevant issues will allow them their providers to align treatment options, as well as psychosocial and community support services, with personal preferences, values, and beliefs.

The results of an effective decision-making process can be documented in a variety of ways, including advance directives. Many forms and tools are available today that are simple for individuals and their families to develop and manage with a range of providers. However, these documents must be accessible at any time, setting, or care location to ensure that individual wishes and preferences are properly followed. A study of EpicCare’s ambulatory EHR system found that even though 51 percent of individuals 65 years of age or older had an advance care planning document, only about one-third of records included a scanned copy of the document with signatures that are required to make the document legally valid.²⁸ Comprehensive and interoperable electronic medical records (EMRs) are key in this effort if they are up-to-date and reflect recent care goals and preferences. These records should be transferrable across the home, hospital, and post-acute care settings, and should protect the privacy of patients and their families.

Barrier	Policy Objective	Solution	Advocacy Actors
Lack of coverage for patient-	Improve access to care planning services	<ul style="list-style-type: none"> ▪ Medicare and Medicaid should cover voluntary advance care planning 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ States

²¹ Center to Advance Palliative Care. 2011. “2011 Public Opinion Research on Palliative Care.” Accessed November 6, 2011. <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>

²² Calabrese-Eck, L. 2013. “Understanding consumer attitudes, barriers, and word-strings around advanced care.” Presented June 27, 2013, at the Consumer Research Symposium. Washington, DC.

²³ Gerteis, M., Edgman-Levitan, S, Daley, J. et al. 1993. *Through the Patient’s Eyes: Understanding and Promoting Patient-Centered Care*. Jossey-Bass Publishers: San Francisco.

²⁴ Lilly CM, De Meo DL, Sonna LA, et al. 2000. “An intensive communication intervention for the critically ill.” *The American Journal of Medicine*, 109, 6, 469-475.

²⁵ Lautrette A, Darmon M, Megarbane B, et al. 2007. “A communication strategy and brochure for relatives of patients dying in the ICU.” *New England Journal of Medicine*, 356, 469-478.

²⁶ Curtis JR, Treece PD, Nielsen EL, et al. 2008. “Integrating palliative and critical care: evaluation of a quality-improvement intervention.” *American Journal of Respiratory Critical Care Medicine*. 178, 3, 269-275.

²⁷ Mosenthal AC, Murphy PA, Barker LK, et al. 2008. “Changing the culture around end-of-life care in the trauma intensive care unit.” *Journal of Trauma*, 64, 6, 1587-1593.

²⁸ Wilson, C., Newman, S., Tapper, S. et al. 2013. “Multiple locations of advance care planning documentation in an electronic health record: Are they easy to find?” *Journal of Palliative Medicine*, 16, 9, 1089-1094.

<p>provider discussions and for the creation of advance directives</p>		<p>services. Clinicians should be paid for upstream advance care planning conversations with beneficiaries led by an interdisciplinary team with physician input.</p> <ul style="list-style-type: none"> ▪ Increase reimbursements for voluntary advance care planning. Incorporate Current Procedural Terminology (CPT) codes for advance care planning consultations into Medicare FFS billing for physician and non-physician providers. Rate-setting approaches for managed care plans (e.g. through Medicare Advantage) and capitated entities should recognize and encourage those core benefits. 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS
<p>Lack of public knowledge regarding advance care planning</p>	<p>Enhance public knowledge of advance care planning and treatment options</p>	<ul style="list-style-type: none"> ▪ Develop and promote public knowledge on the value of advance care planning. Expand public knowledge on advance care planning issues and services for diverse populations and the value of engaging in advance care discussions with providers. Authorize and support the launch of targeted outreach and education in partnership with stakeholders, such as community- and faith-based organizations that builds a common understanding of what advance care entails, how to have the conversations between individuals and their families, and providers, and 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ Private stakeholders ✓ States

		<p>its value.</p> <ul style="list-style-type: none"> ▪ Revise Medicare & You Handbook. CMS should further develop and enhance information on advance care planning in the Medicare & You Handbook to ensure the 65+ population understands the value of advance care, the range of options available, and how to engage in conversations with providers. ▪ Disseminate PSDA compliance best practices. Although the Patient Self-Determination Act (PSDA) requires the provision of information about advance care planning, implementation varies widely. Federal officials, the Joint Commission, and hospital associations should identify and disseminate best practices concerning PSDA compliance and improvement and those practices which actually help us define advance care planning (i.e. knowing and honoring individuals' wishes). 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ HHS/CMS ✓ Private stakeholders
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<p>Care plans may not be reviewed as needed or transferrable across care settings</p>	<p>Facilitate documentation of various components of care plans and ensure accessibility across providers and settings</p>	<ul style="list-style-type: none"> ▪ Require or incent the creation of interoperable EHRs that facilitate advance care planning across sites of care, providers, and through the course of an illness. As part of Stage 3 Meaningful Use, require or incent recording of advanced care plans, advance directives, and verification that preferences are recorded, and that information is accessible in home or care settings. Specifically, EHRs should document the following: 1) designation of a surrogate or decision maker, 2) individual care goals and preferences, 3) advance directives, and 4) medical orders for life-sustaining treatment for targeted populations. ▪ Increase portability of advance directives, POLST forms for those that are seriously ill, living wills, and durable powers of attorney (DPAs) across health systems and from state to state. Regardless of where a patient receives care, their care preferences should always be easily accessible. Policymakers should investigate and incent the development of tools (e.g. national registries) that allow for a range of advance directive formats to be accessed in different care settings from third-party sources, 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/ONC ✓ Congress ✓ HHS/ONC ✓ States
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		<p>including from managed care plans. Legal barriers to honoring preferences at the state and federal levels, such as statutorily mandated forms, should be repealed.</p> <ul style="list-style-type: none"> ▪ Identify best practices in advance and urgent care planning. State licensing and survey officials, ombudsman organizations, and care facilities should work cooperatively to develop care planning approaches that meet regulatory requirements and reflect the best models of resident- and family-centered care through careful delineation of goals of care upon admission, integrating effective care planning into periodic family meetings, and documenting care plans in a clear and actionable fashion. Care planning is needed when advanced illness is diagnosed and not just when individuals are admitted to acute settings, such as an intensive care unit (ICU). ICU-related care planning is often too delayed. Hospital associations, critical care physicians, palliative care specialists, and bioethics organizations should develop best practices for timely care planning. 	<ul style="list-style-type: none"> ✓ States ✓ Private Stakeholders
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III. Engage individuals with advanced illness, their families, and caregivers with a full range of supports and services

Family caregivers have increasingly expanded roles and responsibilities in caring for those with advanced illness. As a result, they often experience significant financial, emotional, physical, and psychological burden. Approximately 65 million Americans – nearly 30 percent of adults – are caregivers that provide 20 hours of care per week on average, including assistance with activities of daily living.²⁹ During the last year of an ill person’s life, family care averages nearly 66 hours per week.³⁰ While the burden today on caregivers is significant, it is only projected to worsen as the U.S. population ages. The ratio of potential caregivers, aged 45 to 65 years, for individuals 80 years of age or older is projected to decrease from 7:1 to 4:1 from 2010 to 2030, and to 3:1 by 2050.³¹

There is insufficient training and support for this shift of medical care from the nurse to the family caregiver. In many cases, caregivers have had no training to perform these tasks and have to learn on their own.³² A recent report issued a call for collective action, from across professions, to support family caregivers.³³ To reduce these burdens, caregivers and families should have access to a full, comprehensive range of benefits and resources to: [1] inform and educate them regarding their loved ones’ condition and available resources and tools and [2] provide a complete array of services to address their emotional, psychological, physical, and financial needs.

Barrier	Policy Objective	Solution	Advocacy Actors
Lack of regular assessments of caregiver needs	Enhance assessments on caregiver needs through Federal health programs	<ul style="list-style-type: none"> ▪ Require Medicaid HCBS Waiver programs to collect data on caregiver needs. Require that family caregiver needs be included in 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS /CMS ✓ States

²⁹ National Alliance for Caregiving. 2009. *Caregiving in the U.S.* Accessed October 15, 2014. http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf

³⁰ Rhee, Y, Degenholtz, H., LoSasso, A. et al. 2009. “Estimating the quantity and economic value of family caregiving for community-dwelling older persons in the last year of life,” *Journal of the American Geriatrics Society*, 57, 1654-1659.

³¹ Redfoot, D., Feinberg, L., & Houser, A. 2013. *The aging of the baby boom and the growing care gap: A look at future declines in the availability of family caregivers.* Accessed October 15, 2014. http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf

³² Reinhard, S., Levine, C., & Samis, S. 2012. “Home Alone: Family Caregivers Providing Complex Chronic Care.” Accessed November 6, 2014. <http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html>

³³ Ibid.

		<p>assessment tools for Medicaid Home and Community-based Services (HCBS) waiver programs when family caregivers are required to execute the treatment plan. This includes a conversation with the family caregiver him/herself. The caregiver assessment should be part of the EHR.</p> <ul style="list-style-type: none"> ▪ Use Medicare annual visits to assess family caregiver needs. Encourage Medicare providers that conduct annual visits to assess if beneficiaries are also caregivers and potential risks to their health from caregiving, including physical strain, emotional stress, and depression. 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS
<p>Lack of complete information and educational resources for caregivers</p>	<p>Create and disseminate informational resources aimed at caregivers</p>	<ul style="list-style-type: none"> ▪ Provide a full range of informational resources to direct caregivers to available supports. To the extent possible, leverage existing resources, including online sources, to direct caregivers towards the proper supports and resources. The Older Americans Act can be amended to authorize increased funding for family caregiving training materials on advanced care, including the range of treatment and planning options that can be considered. 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS ✓ Stakeholders
<p>Lack of health and community services and supports for</p>	<p>Promote provision of person- and family - centered care that meets continuum of</p>	<ul style="list-style-type: none"> ▪ Assess continuum of needs individuals and caregivers have to provide person-centered care. Individuals 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ Private stakeholders

<p>individuals and caregivers</p>	<p>needs</p>	<p>with advanced illness have both health and social needs in many cases. When individuals are not connected to community-based and social service organizations to meet non-medical needs (e.g. food, transportation, etc.), health outcomes can be negatively affected. Advance care planning programs should assess continuum of health and social needs and employ population health management strategies to link individuals to necessary supports and services.</p>	
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IV. Strengthen professional education and engagement in collaborative, team-based models of person- and family- centered care delivery

Transforming advanced care delivery requires that clinicians and direct care workers receive specialized training across the advanced care continuum. Targeted educational tools and resources could inform the care team on the spectrum of advanced care interventions across the care continuum. While many current training programs are focused on palliative and hospice care, expanding professional education and training resources for all members of the care team on the full spectrum of advanced care interventions is necessary to successfully manage advanced illness.

The IOM report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, found two major workforce gaps. First, knowledge gains on caring for those with advanced illness have not generally resulted in knowledge transfer to providers on the front lines.³⁴ Second, there continues to be an insufficient number of palliative care providers.³⁵ A 2008 survey of 128 U.S. medical schools found that of the approximately 60 that responded only 14 had a required course on palliative care.³⁶ Most importantly, teaching palliative care has an impact on medical students. An assessment of one didactic

³⁴ Institute of Medicine. 2014. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. National Academies Press: Washington DC.

³⁵ Ibid.

³⁶ Van Aalst-Cohen, E., Riggs, R., & Byock, I. 2008. "Palliative care in medical school curricula: A survey of United States medical schools." *Journal of Palliative Medicine*, 11, 9, 1200-1202.

program found a 23 percent improvement in student knowledge and a 56 percent improvement in their feelings of competence on the topic.³⁷

Unfortunately, insufficient training among providers may be contributing to a disconnect between patient preferences and treatment outcomes. For instance, in one study 92 percent of individuals had stated a preference for care forums on comfort, but the researchers found that this was “poorly correlated with treatment delivered.”³⁸ On the other hand, access to a stable provider that can coordinate care across settings has been shown to improve end of life care for cancer patients. A literature review of end of life care coordination for individuals with cancer found that continued involvement of primary care physicians was valuable, that it influenced how caregivers felt about their experience and outcomes, and perhaps most critically helped patient communication and emotional support needs.³⁹

Barrier	Policy Objective	Solution	Advocacy Actors
<p>Workforce supply issues and the lack of advanced illness-focused training</p>	<p>Enhance professional education and engagement</p>	<ul style="list-style-type: none"> ▪ Establish career incentive awards via grants and contracts for providers that teach or practice palliative care for a minimum number of years. Incentives for those that teach or practice palliative care could include loan forgiveness or other financial incentives. ▪ Increase interdisciplinary training programs for medical fellows and residents. Exempt palliative medicine fellowships from graduate medical 	<p>✓ Congress</p> <p>✓ Congress ✓ Professional associations</p>

³⁷ Von Gunten, C., Mullan, R., Nelesen, M. et al. 2012. “Development and evaluation of a palliative medicine curriculum for third-year medical students.” *Journal of Palliative Medicine*, 15, 11, 1198-1217.

³⁸ Kelley, A., Ettner, S., Morrison, Q. et al. 2011. “Determinants of medical expenditures in the last 6 months of life.” *Annals of Internal Medicine*, 154, 4, 235-242.

³⁹ Han, P. & Rayson, D. 2010. “The coordination and primary and oncology specialty care at the end of life.” *Journal of the National Cancer Institute Monographs*, 40, 31-37.

		<p>education caps or loan cancellation programs. Establish training programs that include an emphasis on provider-patient communication on advance care planning,</p> <ul style="list-style-type: none"> ▪ Evaluate and disseminate best practices on development of interdisciplinary teams in advanced care. HHS should fund studies on how to most effectively advance and structure teams and make the most effective use of providers practicing at the top of their licenses. Disseminate findings through targeted physician and other health professional societies, health systems, and payers. ▪ Integrate specialized and interdisciplinary training programs into medical school curriculums. Establish guidelines for a minimum amount of training on advanced illness care, including an emphasis on provider-patient communication, pain and symptom management, and psychosocial and family caregiver assessments, as a requirement for obtaining a degree in both allopathic and 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS ✓ Private stakeholders ✓ Private stakeholders ✓ Professional associations
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		osteopathic medicine.	
Lack of incentives for increased training	Extend financial support for states and select providers	<ul style="list-style-type: none"> ▪ Establish federal grant program to develop palliative care and hospice education programming. Authorize and fund a grant program for states and private stakeholders to develop palliative care and hospice education programming. ▪ Provide incentives to certify direct care workers. Authorize and fund grants to care facilities to: (1) offer continuing training and varying levels of certification to employees who provide direct care and (2) provide bonuses or other benefits to employees who achieve certification. These grants could also support specialized workforce training in symptom assessment and management. 	<ul style="list-style-type: none"> ✓ Congress ✓ HHS ✓ Private stakeholders ✓ Congress ✓ HHS ✓ Private stakeholders
Lack of continuing medical education requirements	Promote ongoing professional education and engagement	<ul style="list-style-type: none"> ▪ Promote continuing education for physicians, nurses, and other health professionals. Require physicians in category I, and other health professionals to complete at least 2 hours of CME devoted to advanced care management every two years. 	<ul style="list-style-type: none"> ✓ Private stakeholders ✓ Professional Associations

Conclusion

Most Americans today are living longer and healthier lives than ever before. Yet at some point the great majority will face advanced illness. Shifting demographics and new knowledge about the gap between the needs and realities of care that those with advanced illness receive have resulted in renewed energy and interest in advanced care. Closing this gap would help address the needs of a growing number of Americans that need and want seamless, person- and family- centered, coordinated care that helps them live as happily, comfortably, and productively as possible. This policy agenda provides wide ranging options that would help transform care for Americans with advanced illness and their caregivers and families. The opportunity to offer care that aligns with individuals’ personal values and goals, and that supports their families and caregivers through the journey is within our reach if stakeholders work with one another, and federal and state policymakers to drive comprehensive change.

Appendix

Abridged Chart of Policy Options

Policy Objective	Solution	Advocacy Actors
Promote advanced care management through payment and delivery reforms	Build on existing federal and state demonstrations and programs to replicate and scale effective advanced care programs.	<ul style="list-style-type: none"> ✓ HHS/CMMI ✓ States
	Increase funding for demonstrations to examine strategies to improve coordination of care across time, care settings, and diagnoses, and provide funding to scale successful innovations nationally.	<ul style="list-style-type: none"> ✓ HHS/CMMI
	Provide incentives for Medicaid programs to increase establishment and use of advanced care programs.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMMI ✓ States
	Create transition payments to facilitate development and adoption of advanced care programs.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ NQF
	Include incentives or requirements for providers to establish or deliver advanced care programs through Medicare value-based payment programs.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ States
Enhance quality measure development	Develop and build consensus around comprehensive quality metrics (process,	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS

	outcomes and patient/family experience) to assess the quality of care delivery through public-private relationships.	<ul style="list-style-type: none"> ✓ NQF ✓ Private Stakeholders
	Create and develop consensus around metrics for appropriate and timely referral to hospice in Medicare.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ NQF ✓ Private Stakeholders
	Create and develop consensus around standard metrics appropriate for persons with advanced illness.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ NQF ✓ Private stakeholders ✓ Professional Associations
	Encourage public reporting of palliative, end of life, and advanced care quality measures through Federal health programs.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ States ✓ Professional Associations
Utilize research and quality measure development to facilitate inclusion of advanced care in new payment models	Develop requirements, standards, and procedures for accreditation of hospital- and community-based palliative care programs.	<ul style="list-style-type: none"> ✓ HHS/CMS ✓ Private stakeholders (NQF, JCAHO)
	Revise criteria for hospice eligibility in Medicare and examine access to hospice for Medicaid beneficiaries.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS
	Amend payment rules for telehealth.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ States
Policy Objective	Solution	Advocacy Actors
Improve access to care planning services	Medicare and Medicaid should cover voluntary advance care planning services.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ States
	Increase reimbursements for voluntary advance care planning.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS
Enhance public knowledge of advance care planning and treatment options	Develop and promote public knowledge on the value of voluntary advance care planning.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ Private stakeholders ✓ States
	Revise Medicare & You Handbook.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS
	Disseminate PSDA compliance best practices.	<ul style="list-style-type: none"> ✓ HHS/CMS ✓ Private stakeholders

Facilitate documentation of various components of care plans and ensure accessibility across providers and settings	Require or incent the creation of interoperable EHRs that facilitate advance care planning across sites of care, providers, and through the course of an illness.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/ONC
	Increase portability of advance directives, POLST forms for those that are seriously ill, living wills, and durable powers of attorney (DPAs) across health systems and from state to state.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/ONC ✓ States
	Identify best practices in advance and urgent care planning.	<ul style="list-style-type: none"> ✓ States ✓ Private Stakeholders
Enhance assessments on caregiver needs through Federal health programs	Require Medicaid HCBS Waiver programs to collect data on caregiver needs.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS /CMS ✓ States
	Use Medicare annual visits to assess caregiver needs.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS
Create and disseminate informational resources aimed at caregivers	Provide a full range of informational resources to direct caregivers to available supports.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS ✓ Stakeholders
Promote provision of person-centered care that meets continuum of needs	Assess continuum of needs individuals and caregivers have to provide person-centered care.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS/CMS ✓ Private Stakeholders
Policy Objective	Solution	Advocacy Actors
Enhance professional education and engagement	Establish career incentive awards via grants and contracts for providers that teach or practice palliative care for a minimum number of years.	<ul style="list-style-type: none"> ✓ Congress
	Increase interdisciplinary training programs for medical fellows and residents.	<ul style="list-style-type: none"> ✓ Congress ✓ Professional Associations
	Evaluate and disseminate best practices on development of interdisciplinary teams in advanced care.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS ✓ Private Stakeholders
	Integrate specialized and interdisciplinary training programs into medical school curriculums.	<ul style="list-style-type: none"> ✓ Private Stakeholders ✓ Professional Associations
Extend financial support for states and select providers	Establish federal grant program to develop palliative care and hospice education programming.	<ul style="list-style-type: none"> ✓ Congress ✓ HHS ✓ Private Stakeholders
	Provide incentives to certify direct care	<ul style="list-style-type: none"> ✓ Congress

	workers.	<ul style="list-style-type: none"> ✓ HHS ✓ Private Stakeholders
Promote ongoing professional education and engagement	Promote continuing education for physicians, nurses, and other health professionals.	<ul style="list-style-type: none"> ✓ Private Stakeholders ✓ Professional Associations