



June 22, 2015

The Honorable Orrin Hatch
Chairman, Senate Finance Committee
United States Senate
Washington, DC 20510

The Honorable Ron Wyden
Ranking Member, Senate Finance Committee
United States Senate
Washington, DC 20510

The Honorable Johnny Isakson
Co-Chair, Chronic Care Working Group
United States Senate
Washington, DC 20510

The Honorable Mark Warner
Co-Chair, Chronic Care Working Group
United States Senate
Washington, DC 20510

Re: Comments to the Senate Finance Committee's Chronic Care Working Group

Dear Chairman Hatch, Ranking Member Wyden, Senator Isakson, and Senator Warner:

Thank you for the opportunity to provide comments to the Senate Finance Committee's Chronic Care Working Group. We applaud the Finance Committee for establishing a bipartisan working group to review the impact of chronic diseases on Medicare beneficiaries.

The Pew Charitable Trusts is an independent, non-profit research and public policy organization. The Trusts' project to improve end-of-life care advances policies that help people make informed decisions about their treatment preferences, improve the documentation of these preferences, and hold health care providers accountable for honoring patient wishes and delivering high-quality care. Additionally, the project highlights innovative ways of providing care to seriously ill people and their families as they near the end of their lives.

We urge the Working Group to provide greater support for chronically ill beneficiaries and those near the end of life by:

- 1) Encouraging the completion of advance care plans
- 2) Improving accessibility of advance care plans
- 3) Strengthening the quality measures for palliative and end-of-life care
- 4) Supporting the development and evaluation of new care models

These goals fit into the overarching policy objective of your initiative. Specifically, ongoing, high-quality, coordinated palliative care will improve the overall care for this uniquely vulnerable population.

Palliative Care and Advance Care Planning

A critical part of improving the care for people with chronic illnesses is ensuring that they have access to high-quality palliative care. Palliative care is the medical subspecialty focused on people living with serious and chronic diseases. It provides relief from the symptoms and stress

of a serious illness, whatever the diagnosis. Palliative care is provided by an interdisciplinary team of doctors, nurses, social workers, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and any stage in a serious illness and can be provided starting at the point of diagnosis of a serious illness in conjunction with curative treatment. Key components of palliative care include control of pain, symptoms and side effects, and psychosocial, spiritual and caregiver support. By relieving complex pain and symptoms, palliative care improves a patient's ability to tolerate medical treatments and carry on with daily life. It also empowers patients to play a greater role in their own care by facilitating communication between patients, caregivers, and providers across the care continuum.¹

Significant evidence has demonstrated that patients who access palliative care services have better quality of life and live longer.² Most hospital palliative care programs have been shown to improve physical and psychological symptom management, caregiver well-being, and family satisfaction.^{3,4} Much of the evidence of the value of palliative care to date focuses on the benefits in chronic conditions such as cancer, congestive heart failure and pulmonary disease.⁵ Palliative care has been found to improve care quality for the sickest and most vulnerable patients across diseases and care settings.⁶

An important component of palliative care is advance care planning, which supports patients and families in discussing and documenting care preferences, with the goal of ensuring that the care patients receive is aligned with their goals, values and preferences. People use advance care planning documents to articulate the type of care they want if they cannot speak for themselves; these documents can be revisited periodically. Research shows that advance care planning significantly improves outcomes of care, including increased compliance with patient preferences, fewer hospitalizations, and less intensive treatments.^{7,8,9} The advance care planning process can begin at any stage or state of health, and should center on frequent conversations with family members and care providers.¹⁰

Advance care planning has become the standard of care and consensus regarding the importance and value of these services is widespread. Both the Centers for Disease Control and Prevention

¹ "Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life." 2014. Consensus report. Washington, D.C.: Institute of Medicine. www.iom.edu/endoflife.

² Jennifer S. Temel et al., "Early palliative care for patients with metastatic non-small-cell lung cancer," *New England Journal of Medicine* 363(2010):733-742.

³ Joan M. Teno et al., "Family perspectives on end-of-life care at the last place of care," *Journal of the American Medical Association* 291,no.1(2004):88-93.

⁴ Casarett D. Pickard et al., "Do palliative consultations improve patient outcomes?" *Journal of the American Geriatrics Society* 56, no. 4 (2008): 593-599.

⁵ Literature Review on Advance Care Planning. ASPE RAND (2007) <http://aspe.hhs.gov/daltcp/reports/2007/advdir.pdf>.

⁶ Samantha Smith et al., "Evidence on the cost and cost-effectiveness of palliative care: a literature review," *Palliative Medicine* 28 no.2(2014):130-50.

⁷ Joan M. Teno et al., "Association between advance directives and quality of end-of-life care: a national study," *Journal of the American Geriatrics Society* 55, no. 2(2007):189-194.

⁸ Karen M. Detering et al., "The impact of advance care planning on end of life care in elderly patients: randomised controlled trial," *BMJ* , 340 (2010):c1345.

⁹ Bernard J. Hammes and Brenda L. Rooney, "Death and end-of-life planning in one midwestern community," *Archives of Internal Medicine* 158, no. 4 (1998):383-390.

¹⁰ "Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life." 2014. Consensus report. Washington, D.C.: Institute of Medicine. www.iom.edu/endoflife.

¹⁰ CDC's Healthy Aging Program, Give Peace of Mind: Advance Care Planning (March 3, 2014), available at <http://www.cdc.gov/aging/advancecareplanning/>.

(CDC)¹¹ and the recent Institute of Medicine (IOM) report, “Dying in America” support advance care planning. The IOM states that “advance care planning is essential to ensure that people receive care that reflects their values, goals and preferences.”¹²

Completion of Advance Care Plans

Advance care plans can be a critical component to providing patient centered care to patients with multiple chronic conditions. Unfortunately, most Medicare beneficiaries do not have an advance care plan in their medical record. According to a recent study funded by the Agency for Health Care Research and Quality (AHRQ) only 12 percent of Medicare beneficiaries have developed an advance care plan in conjunction with their medical provider.¹³

One roadblock to the completion of advance care plans is that Medicare does not reimburse providers for having advance care planning conversations. However, in the 2015 Medicare Physician Fee Schedule, the Centers for Medicare & Medicaid Services (CMS) indicated that they will consider whether to pay for the codes related to advance care planning services after they reviewed the submitted comments.¹⁴ Additionally, bipartisan legislation recently introduced in the Senate—the *Care Planning Act*—supports reimbursement for these services. We encourage the Working Group to support this policy change and to examine other barriers to the completion and documentation of advance care plans.

Accessibility of Advance Care Plans

In order to ensure that a patient’s wishes are known and honored, they must be accessible electronically at the time and place of care. This can be difficult to do, as transitions of care are common for very ill patients; a recent study in the *Journal of the American Medical Association* found that people face an average of 3.1 transitions between different care sites in their final 3 months of life.¹⁵ A study in the *Journal of Palliative Medicine* found that as very sick patients were transferred between several care settings, the likelihood that advance care plan information was available in new settings was “no greater than chance.”¹⁶

We encourage the Working Group to support efforts so that the most current version of an advance care plan is accessible to providers across care settings.

Quality Measure Development

Measures are essential tools to ensure that patients are receiving high-quality care. Although Medicare is increasingly using quality measures to assess providers, facilities and health plans, the program lacks sufficient measures for palliative and end-of-life care. For example, there are

¹¹ CDC’s Healthy Aging Program, Give Peace of Mind: Advance Care Planning (March 3, 2014), available at <http://www.cdc.gov/aging/advancecareplanning/>.

¹² “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.” 2014. Consensus report. Washington, D.C.: Institute of Medicine. www.iom.edu/endoflife.

¹³ Joan M. Teno et al., “Advance directives for seriously-ill hospitalized patients: effectiveness with the Patient Self-Determination Act and the SUPPORT intervention,” *Journal of the American Geriatrics Society* 45 (1997):500-7.

¹⁴ The codes are 99497: Advance care planning including the explanation and discussion of advance directive such as standard forms (with completion of such forms, when performed), by the physician or other qualified health professional; first 30 minutes, face-to-face with the patient, family member(s) and/or surrogate); and 99498: Advanced care planning including the explanation and discussion of advance directive such as standard forms (with completion of such forms, when performed), by the physician or other qualified health professional; each additional 30 minutes.

¹⁵ Joan M. Teno et al., “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*. 2013;309(5):470-477. doi:10.1001/jama.2012.207624.

¹⁶ Victoria Y. Yung et al., “Documentation of Advance Care Planning for Community-Dwelling Elders.” *Journal of Palliative Medicine* (2010) 13 (7): 861–67.

currently no palliative related measures in the Medicare Advantage Five-Star Quality Rating System, the Medicare Shared Savings Program, or the Hospital Inpatient Quality Reporting Program. The National Quality Forum (NQF) Measures Application Partnership has repeatedly cited palliative care as a high leverage measure gap, and the Institute of Medicine's Report "*Dying in America*" also stressed the needs for better measurement in this area.

Accordingly, we urge the Working Group to encourage CMS to develop and test quality measures specific to palliative care services. In particular, the agency needs measures that are applicable across sites of care and specific to people with serious illnesses near the end of life.

Continued Support for New Models of Coordinated Care

The Center for Medicare & Medicaid Innovation has funded a number of groundbreaking models in delivering services to individuals in need of palliative and end-of-life care. For example, the Medicare Care Choices Model will allow hospice-eligible beneficiaries not enrolled in hospice to continue concurrent curative care services. However, there is a need for additional models to be tested that address the care of beneficiaries with multiple chronic conditions throughout the care continuum. We encourage the Working Group to direct CMMI to support new models to support Medicare beneficiaries with chronic conditions near the end of life, evaluate these models, and disseminate the findings.

Thank you for considering Pew's comments. Should you have any questions or if we can be of assistance, please contact Josh Rising at jrising@pewtrusts.org or 202-540-6761.