

**STATEMENT FOR THE RECORD**

*On*

**The Right Care at the Right Time: Ensuring Person-Centered Care for Individuals with Serious Illness.**

*Submitted to*

**United States Senate Special Committee on Aging**

*By*

**The Pew Charitable Trusts**

*On*

**June 23, 2016**

Chairman Collins, Ranking Member McCaskill, and distinguished Members of the Committee, The Pew Charitable Trusts (Pew) thank you for the opportunity to provide a statement for the record on the importance of improving end-of-life care.

Pew is an independent, non-profit research and public policy organization. Pew's project on improving end-of-life care seeks to expand access to advance care planning, develop tools to measure the quality of care, highlight innovative ways of providing care to seriously ill people and their families, and improve documentation of patients' wishes for their care near the end of life.

### **Overview**

Sooner or later, most of us will have to make plans for end-of-life care—for a parent, a spouse, or for ourselves. Modern medicine gives us many options, from aggressive treatments to pain relief and comfort care, but all too often individuals with advanced illness find themselves not getting the care they want and without the opportunity to articulate their personal values, preferences and the care that they want. Public opinion surveys consistently show approximately seven in 10 Americans prefer to die at home; unfortunately less than one-third actually do. Most people die in institutional settings that range from nursing homes to hospital intensive care units.

Recent data gives mixed signals on the quality of care received near the end of life. One study shows that providers are doing a better job discussing a patient's religious and spiritual concerns and communicating with bereaved families than in earlier years.<sup>1</sup> But a comparison of billing data also shows increased use of intensive care units at the end of life, more late referrals to hospice care, and an increased rate of rehospitalization during the last 90 days of life. A fragmented medical system and a lack of communication among doctors, patients, and families contributes to a less than optimal patient experience.

With an estimated 83 million seniors enrolled in Medicare by 2050, it is time for Congress to take up bipartisan proposals that would address the various aspects of palliative and end of life care. Medicare's decision last year to reimburse health care providers when they discuss end-of-life care was a needed first step. With their knowledge of a patient's history, trusted family doctors can help patients create advance care plans that document their wishes in case illness or accident prevents them from speaking for themselves. With broad support from experts in the field and organizations representing consumers, clinicians and faith communities, Congress could take the next step and pass bipartisan legislation to help ensure that an individual's wishes are documented and carried out and that they have access to quality care.

### **Recommendations**

#### **Implementing Quality Metrics for Palliative and End-Of-Life Care**

Quality metrics—tools used to assess health care processes or patient outcomes against recognized standards—are effective in encouraging health systems and insurers to improve the care they provide. We have many measures to assess the quality of care for common illnesses

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<sup>1</sup> Joan Teno, Vicki Freedman, Judith Kasper, Pedro Gozalo and Vincent Mor, "Is Care for the Dying Improving in the United States?", 2015, *Journal of Palliative Medicine* 18, no. 8. DOI: 10.1089/jpm.2015.0039.

that require acute care. For example, there are standard medications that have been proven to help patients recover from heart attacks; quality measures are in place to judge whether such drugs are being prescribed as they should be. Yet few good measures exist to assess the care that patients receive near the end of life, and determine whether it is consistent with their goals and wishes for treatment.

We urge Congress to pass legislation that would direct Medicare to develop, test and adopt quality measures that are appropriate for palliative and end-of-life care. Such legislation would prioritize and fund the development of quality measures that address the concordance between the individual's stated goals, values, and preferences with documented care plans, the treatment that is delivered, and the outcome of treatment. Addressing this deficiency is a critical step in ensuring that health systems and insurers to improve the care they provide.

#### Encouraging States to Improve Physician Orders for Life Sustaining Treatment (POLST)<sup>1</sup>

POLST is a process that translates a patient's goals for care near the end of life into medical orders documented on a brightly colored form. The form is designed to effectively capture people's wishes and make these preferences accessible to health care professionals as medical orders that are honored throughout the health care system. The process results in a medical order signed by a health care professional and in many states by the individual or a legally authorized surrogate as well. The use of POLST increases the likelihood that the site of death will correspond with a person's stated preferences.

A POLST form is not for everyone. Unlike advance directives, these forms are intended only for seriously ill or frail individuals whose condition is such that their doctors would not be surprised if they died within the next twelve months. In contrast, advance directives do not give orders to Emergency Medical Services and must be interpreted by a physician before they are determined to be in effect. Additionally, POLST forms are designed to physically stay with the patient or be included in the patient's electronic health record or state registry where they will be easily available in an emergency.

POLST is a good example of the dynamic work that can be done at the state level with the support of a diverse group of stakeholders. Unfortunately, few states have the resources to engage in outreach and education to consumers and clinicians; fewer have the ability to maintain such outreach over time. Pew supports the provision of federal funding in the form of grants to the states, which is seen by many experts as the best way to expand and improve the quality of POLST programs for this singular type of advance care planning document.

#### Ensuring Advance Directive Accessibility Across Health Care Settings

Even when patients document their treatment preferences in advance directives, these forms are frequently unavailable when needed most. Making these advance care planning documents, including POLST forms, easily accessible electronically at the time and place of care will help ensure that a patient's wishes are known and honored. We support legislation that would ensure that these documents can be easily found in the electronic health record and that advance care plans follow people as they move from one care setting to another. Pew also supports legislation that would direct the administration to study the use, portability and electronic storage of

advance directives, including issues that may remain unresolved after Stage 3 Meaningful Use regulations were promulgated.

Supporting Evaluation And Dissemination Of Promising End-Of-Life Care Delivery Models  
Medicare, Medicaid, and a number of health care systems have created innovative models to support high quality care, yet few focus on the needs of patients and their families near the end of life. The federal government should fund more demonstration projects that focus on palliative care, evaluate promising models, and disseminate any successful components. We support legislation that directs the Department of Health & Human Services to undertake a demonstration focused on advanced illness management—either by itself or in conjunction with an ongoing effort to enable at least some individuals enrolled in Medicare to access both curative treatment and hospice care.

### Legislation

Existing bipartisan legislation has been introduced in both chambers that would increase access to advance care planning and improve patient care near the end of life. Such bills include:

- The *Care Planning Act*, introduced by Senators Isakson (R-GA) and Warner (D-VA);
- The *Personalize Your Care Act*, introduced by Representatives Phil Roe (R-TN) and Earl Blumenauer (D-OR); and
- The *Compassionate Care Act*, introduced by Senators Richard Blumenthal (D-CT) and Shelley Moore Capito (R-WV).

Each of these bills would address important flaws in the way our current health system handles palliative and end-of-life care and has the potential to greatly improve patient care. With broad support from experts in the field and organizations representing consumers, clinicians and faith communities, these pieces of legislation would help ensure that an individual's wishes are documented and carried out.

We appreciate your leadership on advancing palliative and end-of-life care and we look forward to working with you to improve access to advance care planning services and improve patient care during the end of life. Improving end-of-life care will require new ideas across all elements of the health care sector, from integrated health systems to private insurance companies and hospitals system to individual doctors and patients. We can all take part by having frank conversations with our families and physicians. We encourage Congress to act by passing policies, such as those contained in these bipartisan bills, that will help patients and their families get the care they want in a more patient-centered health system.

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<sup>i</sup> POLST is known by many names, including MOLST (Medical Orders for Life-Sustaining Treatment), MOST (Medical Orders for Scope of Treatment), POST (Physician Orders for Scope of Treatment), LaPOST (Louisiana Physician Order for Scope of Treatment), COLST (Clinician Orders for Life-Sustaining Treatment), IPOST (Iowa Physician Orders for Scope of Treatment), SMOST (Summary of Physician Orders for Scope of Treatment), TPOPP (Transportable Physician Order for Patient Preference), and WyoPOLST (Wyoming Provider Orders for Life-Sustaining Treatment). For simplicity, the term POLST is used when referring to POLST forms or programs in general.