



Improving End-of-Life Care

The problem

As a result of advances in public health and the development of lifesaving medical technology, Americans live longer than ever. Death, when it comes, often follows a chronic or progressive illness.

Unfortunately, the care received near the end of life often does not reflect a person's values, goals, and informed preferences. Although the majority of people say they would prefer to die at home, two-thirds of Medicare beneficiaries die elsewhere, such as a hospital's intensive care unit. People frequently endure unwanted treatment and suffer from inadequate pain management and shortness of breath which often puts enormous stress on family caregivers. A fragmented medical system and a lack of communication among doctors, patients, and families may result in less than optimal patient experience. But difficulties in the health care system may also be caused by the reluctance of patients, families, and doctors to discuss options and the alternatives to further treatment. Having these conversations early in the course of a serious illness is important, because most people who are near death are unable to communicate their wishes.

Pew seeks to improve end-of-life care by advancing 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 will highlight innovative ways of providing care to seriously ill people and their families as the patients reach the end of their lives.

Main project goals

Establish Medicare reimbursement for advance care planning.

Advance care planning is the ongoing process by which people, together with their families and health care practitioners, consider their values and goals and articulate preferences for future care, should they become

unable to speak for themselves. These discussions should always be voluntary and will be different depending on an individual's health status.

One of Pew's major goals was achieved in January 2016 when Medicare began reimbursing providers for time spent on advance care planning. Research shows that advance care planning conversations significantly improve patient outcomes. For example, patients who have these conversations receive care more consistent with their wishes, have fewer hospital admissions, use hospice more regularly, and are more likely to die in their preferred location.

Implement 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. Although progress has recently been made in the use of quality measures in hospice care, these tools remain underused elsewhere, such as hospitals or nursing homes, to evaluate end-of-life care and palliative care, which is designed to improve the quality of life for patients with serious illnesses and help their families. In addition to making better use of existing metrics, health care practitioners need to develop and test new quality measures that are applicable across sites of care and specific to people with serious illnesses near the end of life.

Encourage states to improve Physician Orders for Life Sustaining Treatment (POLST) programs.

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. POLST is appropriate for patients whose condition is such that their doctors would not be surprised if they die within the next 12 months. POLST forms are important in part because they follow patients across care settings. The National Quality Forum, the Institute of Medicine, and other experts have called for a nationwide implementation of POLST.

Ensure 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, accessible electronically at the time and place of care will help ensure that a patient's wishes are known and honored.

Support 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 people 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.

This fact sheet was updated on March 23, 2016, to reflect Medicare's decision to reimburse providers for advance care discussions with patients.

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