Hospice and Palliative Care

This system of specialized palliative care now supports a majority of dying patients in the United States.

The US hospice care movement began in the 1970s with a small number of committed advocates seeking a more humane alternative to end-of-life care. Although healthcare was modernizing, the medical establishment's focus on curative medicine (seeking to cure patients) over palliative care (relieving the symptoms and stress of a serious illness) meant that too often hospital professionals misunderstood or ignored dying people's wishes, and patients perished in pain and distress.

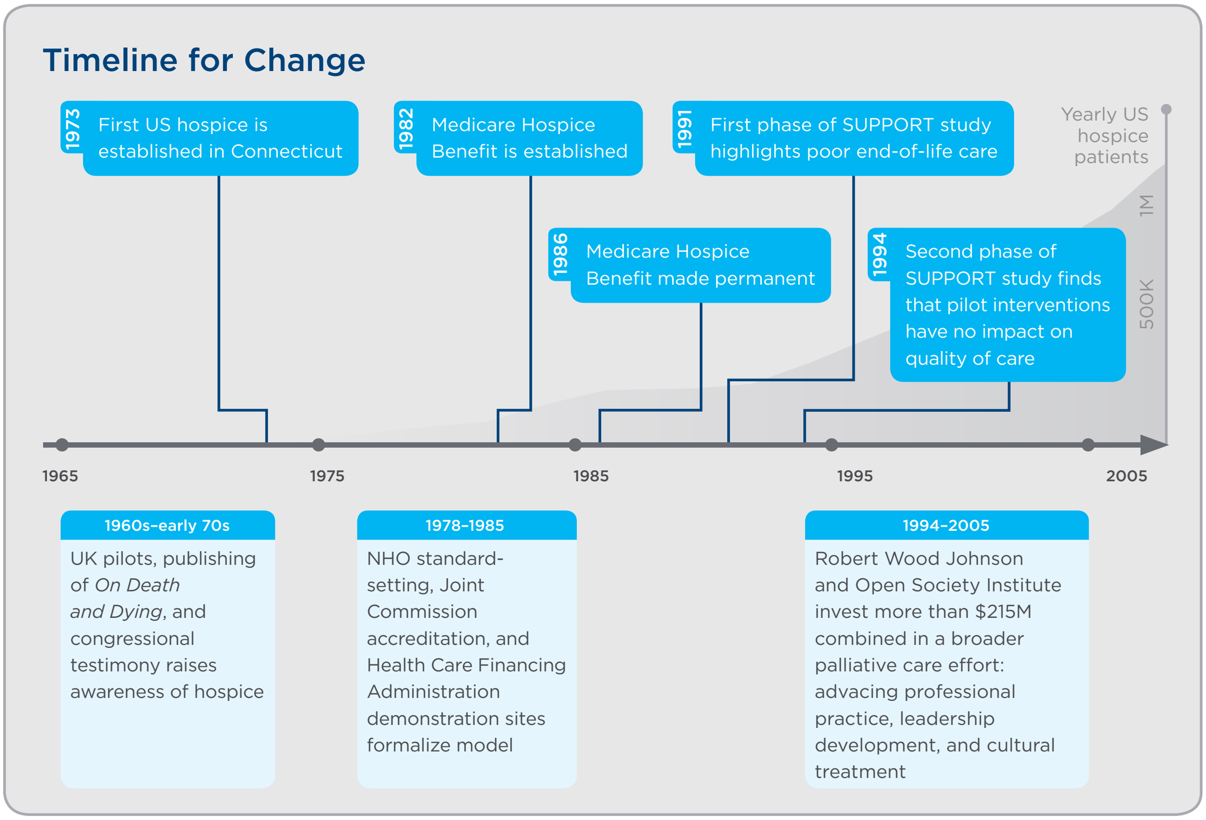
Advocates established the first US hospice in Connecticut in 1973 in order to create an environment of support and dignity for dying patients. By 2013, US hospices served more than 1.5 million patients annually, a figure equal to almost 60 percent of *all* deaths in the country (including sudden deaths, for which hospice and palliative care is not relevant).

How did the hospice movement tip the scales of change? The earliest hospices relied heavily on volunteers and were funded with piecemeal philanthropy. In 1978 the CEO of the Connecticut Hospice urged the broader volunteer movement to form an organizing body, the National Hospice Organization (NHO). That year also saw the start of both federal government endorsement, with a Department of Health, Education, and Welfare task force validating the approach, and federal research funding through the National Cancer Institute. By 1979, the NHO and its leaders published a set of common standards of

This case study is part of a series that accompanies The Bridgespan Group article "Audacious Philanthropy: Lessons from 15 World-Changing Initiatives" (*Harvard Business Review, Sept/Oct 2017*). See below for 15 stories of social movements that defied the odds and learn how philanthropy played a role in achieving their life-changing results.

- The Anti-Apartheid Movement
- Aravind Eye Hospital
- Car Seats
- CPR Training
- The Fair Food Program
- Hospice and Palliative Care
- Marriage Equality
- Motorcycle Helmets in Vietnam
- The National School Lunch Program
- 911 Emergency Services
- Oral Rehydration
- Polio Eradication
- Public Libraries
- Sesame Street
- Tobacco Control

practice for hospice care to enable certification and quality control, and began advocating for Medicare reimbursement.



Timeline for Change

1973 First US hospice is established in Connecticut

1982 Medicare Hospice Benefit is established

1986 Medicare Hospice Benefit made permanent

1991 First phase of SUPPORT study highlights poor end-of-life care

1994 Second phase of SUPPORT study finds that pilot interventions have no impact on quality of care

1960s–early 70s
UK pilots, publishing of *On Death and Dying*, and congressional testimony raises awareness of hospice

1978–1985
NHO standard-setting, Joint Commission accreditation, and Health Care Financing Administration demonstration sites formalize model

1994–2005
Robert Wood Johnson and Open Society Institute invest more than $215M combined in a broader palliative care effort: advacing professional practice, leadership development, and cultural treatment

While the NHO was (and remains today) largely supported by volunteers and member dues, philanthropy has helped the movement over each hurdle of institutionalizing palliative care in the US health system. In the early 1980s, the W.K. Kellogg Foundation (WKKF), Robert Wood Johnson Foundation (RWJF), and others invested significantly to formalize and institutionalize the concept through both standard-setting and advocacy. Indeed, in 1982, an NHO-led advocacy campaign (with support from WKKF) helped to win congressional approval for a Medicare Hospice Benefit.

In the 1980s and 1990s, as hospice developed more widespread awareness and acceptance from both patients and providers, RWJF continued to invest in understanding the quality of end-of-life care. The foundation’s SUPPORT study revealed startling deficiencies in the growing field, suggesting the need for a dramatic change in mindset and approach by the medical establishment. Its results led to deep investment to significantly advance the field of end-of-life care and much more firmly embedded end-of-life care in a broader field, which included hospice. The broader field—palliative care—would apply to more patients, in more cases, and be part of hospital care—and would move hospice into the mainstream medical establishment. Through the 1990s and 2000s, RWJF and the Open Society Institute spent a combined $215 million (almost $275 million in 2017 dollars) advancing this concept. Through their investments to improve professional practice, develop the talent base, and gain widespread cultural acceptance, the quality, availability, and utilization of hospice and palliative care significantly increased during this period.

Philanthropy’s Role in Large-Scale Change

Our research shows that breakthrough social initiatives share a set of five practical approaches to large-scale change. In the case of hospice care, philanthropy played a pivotal role across four of them:

- **Build a shared understanding of the problem:** Cicely Saunders’s early lectures at Yale and Elizabeth Kübler-Ross’s 1969 book, *On Death and Dying*, helped to raise awareness and understanding of the problem. Later the Robert Wood Johnson Foundation (RWJF) and the Open Society Institutes (OSI) funded efforts to study and publicize problems with end-of-life care.
- **Design for massive scale at the outset:** Philanthropy partially funded creation of the evidence base and care standards that made it possible for Medicare reimbursement to become the viable economic model to scale hospice care across the country. W.K. Kellogg Foundation invested in the National Hospice Organization directly, and in a project that led the Joint Commission to begin accrediting hospices in 1984. RWJF and others invested in studying hospice demonstration sites, which revealed the potential cost benefits of the hospice concept.
- **Drive demand, don’t assume it:** OSI and the RWJF helped to fund documentaries and other cultural touch points in the 1990s and 2000s (like Bill Moyers’ PBS series “On Our Own Terms,” at the time the most widely watched series in public television history), to help drive widespread awareness of the problem and acceptance of hospice and palliative care. RWJF and OSI also supported the integration of palliative care into hospitals and the creation of an official medical subspecialty that made palliative care part of mainstream medical education. As a result, 75 percent of today’s hospital patients are in a hospital with a palliative care team.
- **Embrace course correction:** By the mid-1990s, RWJF’s SUPPORT study revealed that startling problems in end-of-life care remained common. As a result, philanthropic investment began to focus much more deeply on systematically improving and embedding compassionate end-of-life care into the medical mainstream, while also addressing the cultural barriers to its widespread acceptance among both medical professionals and society at large.

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