

A Brief History of Hospice Care



Hospice care has been around in one form or another since the 11th century, but the modern approach to end of life care has only been around since the late 1960s.

What is hospice care?

Hospice care places its focus on comfort, quality of life and the wishes of patients with terminal, life-limiting illnesses. It takes an individual approach to care, taking into account the patient's physical, emotional, spiritual, and/or social needs. Hospices provide comfort and care to alleviate a patient's pain and symptoms, instead of life-prolonging treatments which may be traumatic or go against the patient's wishes.

Where did hospice care originate?

'Hospice' comes from the Latin word *hospitum*, meaning hospitality, or a retreat for the ill and weary. There is evidence that the first hospices were found in Malta sometime around 1065. Malta was perfectly placed to provide respite for pilgrims and travelers as well as the ill and dying who were going to and from the Holy Land. With the rise of the European Crusading movement in the 1090s, these early hospices inspired others to establish places dedicated to the care of the terminally ill.

The early hospice care was provided by

various religious orders, such as the Knights Hospitaller of St. John of Jerusalem, who opened the first hospice in Rhodes in the early 14th century. As these orders were dispersed, hospice care faded away, to see a revival in the 17th century in France. Gradually, the provision of hospice care spread throughout Western Europe and Australia.

The pioneering work of Dr. Cicely Saunders in revolutionizing hospice care

The birth of modern hospices as a place dedicated solely to end-of-life care started with the work of British physician, Dame Cicely Saunders. Born in 1918, Saunders was a British nurse who later trained and qualified as a doctor. She suffered from chronic health issues, giving her a strong sense of compassion for her patients. One of these patients, a dying Polish refugee named David Tasma, inspired her to become a hospice activist, and left her a large donation in his will so that she could build on the work she had done with terminally ill patients.

Saunders adopted a 'total pain' management approach, taking into account the psychological, spiritual and physical needs of the individual, as well as considering their family and caregivers.

She continued to adapt and improve her philosophy during her time volunteering at a hospice facility during the 1950s while she furthered her studies to become a doctor.

In 1967, she established St. Christopher's Hospice in south London, the first modern hospice.

Challenges to the hospice movement

Although Saunders transformed the care offered to the terminally ill, it was not without some controversy. Saunders and other important figures in the hospice movement had to deal with a number of issues, such as the cultural taboos against discussing death and terminal illness. Many doctors were resistant to implementing new approaches, while there were many patients and families who struggled with the notion of moving away from a cure towards comfort instead.

The continued growth of the hospice movement

Despite these challenges, Saunders continued to work tirelessly on behalf of the terminally ill. In 1963, she gave a talk at Yale University to an audience of doctors, nurses, medical students, and chaplains. She discussed the notion of specialist care for the dying with a focus on comfort care, and showed images of cancer patients before and after they had received hospice care. The difference in their appearance and wellbeing was undeniable and Saunders' talk prompted the American medics to consider

how they could improve end-of-life care.

America's first hospice

Florence Wald founded the Connecticut Hospice, America's first hospice in 1974. She had attended Saunderson's talk and been inspired by what she'd heard. Wald had found much to consider in the approach of providing support and comfort to the terminally ill and their families rather than carrying out traumatic procedures which did little to alleviate suffering. In her words, at the time, "terminally ill patients went through hell, and the family was never involved."

The rise in support for hospice care

Another leading light in the hospice movement was Dr. Elisabeth Kubler-Ross. The author of *On Death and Dying*, she highlighted the benefits of home care over institutionalized treatment and argued that everyone should have a say in their end-of-life care. She also testified in front of a 1972 US Senate Special Committee on the matter. However, it wasn't until 1986 that the Medicare Hospice Benefit was introduced with the option for states to include hospice care in their Medicaid programs.

Since that time, funding has improved for hospice care and the number of providers has risen to over 5,500. In 2017, over 1.49 million Medicare beneficiaries received hospice care for a day or more. ■