Testimony before the Senate Special Committee on Aging

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Thank you, Chairman Collins and Members of the Committee, for this opportunity to speak to you on the subject of hospice and end of life care.

My name is Katherine Pope, and I am a physician, an anesthesiologist, from Portland, Maine. I have been in medicine for over 30 years, in the practice of clinical anesthesiology in tertiary and ambulatory surgical settings. My experience also includes leadership in medical group management, board service in several organizations related to healthcare including Maine Medical Center, and as co-founder of Hospice of Southern Maine, where I also served as administrative medical director.

Although I have learned much and been involved in hospice services and palliative care for many years, I am not the most knowledgeable or authoritative voice here before you. The perspective I have to offer is as a community volunteer who along with others endeavored to address a serious healthcare gap in my state of Maine, a gap in the care of our most vulnerable patients, the dying. In some ways, my role echoed the tradition and history of hospice in its earlier days in the 1970s and 1980s as a volunteer-driven movement, and volunteerism remains an integral element of the culture of hospice care today. In more recent years, end of life care has evolved and has improved greatly, hospice and palliative medicine (HPM) has become professional, and to the benefit of all, has entered the mainstream of healthcare. However, we all must recognize despite the progress that significant barriers and challenges remain to be addressed.

It was suggested to me that I speak about the history and evolution of hospice in Maine, focusing on the development of the organization Hospice of Southern Maine, established in 2003. That I present a case study, if you will, that may be useful as an example of the origins and current trajectory of end of life care, the challenges then and now.

As an anesthesiologist my professional background is in acute care in a tertiary care hospital, Maine Medical Center, the largest hospital in the state. How does this connect to my personal interest in end of life care? Over my years of practice in the 1980s and 1990s, when comprehensive hospice care in Maine was nearly non-existent and the specialty of palliative medicine was as yet unknown, I witnessed the suffering of many patients with clearly terminal conditions undergoing major surgical procedures, and subjected to unsuccessful and futile resuscitations. This was no one's fault; it was the usual way medical care in acute hospitals was structured and what most families expected: do everything possible to extend life. Hospitals are the very best places for many types of care, but care of the dying is not one of them, particularly in those days when the evolution of what we could do medically outstripped the evolution in attention to quality of life.

Out of this experience came my conviction that good, or even adequate, end of life care was seriously lacking, and led me to initiate the collaborative community effort that resulted in the founding of Hospice of Southern Maine (HSM). The HSM service area includes the two most populous counties (York and Cumberland), totaling approximately 500,000 people or about 40% of the population of Maine.

At the time we began work on this initiative in 2000, according to Medicare statistics, Maine was ranked 49th in the country in utilization of hospice services, with just 9% of dying patients receiving hospice care. Only Alaska ranked lower. According to other national studies and reports at the time, such as Means to a Better End: A Report on Dying in America, funded by the Robert Wood Johnson Foundation in 2002, Maine's health care delivery also ranked poorly in other aspects of palliative and end of life care as well.

Reports produced in our own state reached the same conclusions:

- The *Maine Health Care Performance Council,* appointed by then Governor Angus King, in its report of 2003, identified hospice utilization as a significant health care system performance indicator, stating, "End of life care for people with terminal illness is an area with increasing options. Hospice services can provide an affirmative, cost-effective, high-quality alternative for people with terminal illness. A high rate of hospice utilization would reflect a health care system that is supportive of appropriate alternatives to hospitalization for people with terminal illnesses."
- The *Maine Hospice Council* identified the lack of any inpatient hospice residences as a significant gap in the health care delivery system in its white paper, Inpatient Hospice Facilities in Maine, published in 2001. The paper noted that 47 states had hospice facilities, most having multiple facilities, but Maine had none.

It was a period of growing awareness of the deficit in good end of life care, with increasing dialogue, both professional and in the community. A referendum in Maine in 2000, to allow physician assisted suicide, was defeated, but also brought focus to the unmet need for relief of suffering. But despite the increase in awareness, there was as yet no unified effort to translate ideas to tangible action, and this is where I was able to play a part, in identifying and gathering together key individuals who shared a common vision and were in a position to make decisions.

The initial Steering Committee, created in 2001, and which I co-chaired, that ultimately established Hospice of Southern Maine, consisted of healthcare and community leaders from both Cumberland and York Counties, united by the shared goal of transforming the fragmented system of home hospice service delivery and creating the needed resource of an inpatient hospice facility for the region.

In addition to concerned community members, leadership from the key healthcare organizations in the region were active in the collaborative effort:

- Maine Medical Center, the tertiary hospital in Portland.

- Southern Maine Medical Center, the largest community hospital in York County.
- Three home health visiting nurse agencies that each had small home hospice programs: HomeHealth Visiting Nurses (Portland), SMMC Visiting Nurses (Kennebunk) and Visiting Nurse Services (Saco).
- Hospice of Maine, an organization of trained volunteers
- Maine Center for Cancer Medicine, the oncology physician group serving the region.

Determining the reasons for low utilization and doing a needs assessment were the first steps in the process. We concluded that a major problem was the fragmented delivery system of hospice care in our region, with multiple small hospices associated with much larger home health agencies, each caring for only a few hospice patients at a time, with insufficient volume to enable focus and consistent care or efficient use of resources. Other challenges and barriers included the lack of physician understanding and confidence in the existing programs, and at that time, many of the oncologists felt that they themselves were the most capable of providing palliative care and did not want to enter their patients into the programs. Because there were variable practices and processes among the small programs, communication with physicians was inconsistent and inadequate, further eroding their confidence in the quality of services. The lack of general public awareness and understanding of end of life care and choices was compounded by the small programs' inability to manage effective outreach and education.

However, there were a few positive factors as well working in our favor. The provider and consumer interest that had been accelerated by the physician assisted suicide referendum increased awareness somewhat and opened up willingness to consider improving the situation. The state government, although always facing budgetary challenges, was supportive and made some bond funds available for development of future inpatient facilities. Hospices had also been exempted some years earlier from CON requirements. And a major factor in bringing parties to the table was that all of the entities involved were non-profits governed by community boards.

The first step in establishing a new organization, in this case a new non-profit hospice agency, is defining the mission and values that will guide all subsequent planning. We developed these early in our collaboration and through the shared the commitment to these principles were able to navigate through thorny issues and challenges.

The HSM Mission of compassion, care and comfort through end of life remains paramount. End of life issues will touch every family, and we believe that care of the dying should be a priority in an ethical and caring society.

The shared Values that HSM adopted continue to foster the culture within the organization and focus the direction goals:

- Pursuit of excellence in the delivery of care and comfort to dying patients and their families, based on accepted practices and sound principles of hospice and palliative care.
- Adherence to professional ethics in all aspects of the organization.

- Commitment to serving the community and respecting its generous support by planning and delivering compassionate and competent services, according to efficient and cost effective models.
- Provision of services without regard to financial status, sex, race, religion, age, national origin, disability, or sexual orientation, within the structure of a non-profit, non-sectarian organization.
- Responsiveness to the needs of those within the organization, by cultivating an atmosphere of respect, trust, cooperation and open communication.
- Commitment to maintaining collaborative and cooperative relationships with other community organizations with aligned missions, such as home health agencies, hospitals, educational institutions, advocacy and volunteer organizations, which are essential for improvement of end of life care throughout the community.

We also developed an initial set of objectives and goals, necessary to guide the development of specific plans and structure of services:

- Deliver comprehensive hospice services through a free-standing, licensed, Medicare certified program consistent with the hospice philosophy, providing physical, emotional, social and spiritual services to patients and their families in the setting most appropriate for the individual patient.
- Implement strategies for increased access to home hospice care, which is recognized as the cornerstone of hospice care.
- Operate a hospice facility, in which excellent inpatient is delivered to patients who require acute pain and symptom management, providing treatment according to current and accepted principles and practices of hospice and palliative care.
- Maintain an internal culture and processes that recognize the vital importance of community ownership and investment in the organization, and that embrace the role of responsible stewardship of the community trust and welfare.
- Implement long range plans to ensure financial stability through careful financial planning and management, prudent growth of program services, and effective and responsible fundraising.
- Develop strategies directed toward providing hospice care in institutional and nursing home settings.
- Maintain smooth and functional referral relationships and the communications necessary to ensure continuity of care as the patient moves across healthcare settings.
- Promote better care of all patients with life limiting or terminal illness by supporting and partnering in development of improved palliative care services in other area healthcare organizations, recognizing that this supportive care is needed, not just in the terminal stages, but throughout the illness experience. Such groups include area hospitals, home health agencies, physicians and other providers, community programs on aging and elder care, and related volunteer organizations.
- Strengthen relationships with area universities and provide educational opportunities in end of life and palliative care for students in multiple healthcare disciplines, including medical, nursing, social work, and others.
- Strengthen relationships with area hospitals and provide education and experience in hospice and palliative care for hospital staff, residents and medical staff.

- Participate in collaborative data collection and research efforts with educational institutions, other providers, advocacy and public policy organizations, in order to contribute to general advancements in end of life and palliative care in Maine.
- Support the general need in the community for a better social framework regarding end of life issues, through advocacy to advance public policy, by supporting community awareness programs, and by encouraging volunteerism.

The history and progress of HSM over the first five years (2003-2008) of its existence included many milestones:

- Planning grants were received from United Way to support the early planning work that focused on greater integration of the delivery system.
- A merged corporate structure was established with 501c3 status in 2003, with the new name of Hospice of Southern Maine, and all state licensure and regulatory issues were resolved.
- A founding Membership Corporation and Board of Directors were established and continue to provide strong community and healthcare leadership. Key Supporting Organizations with board representation included Maine Medical Center, Southern Maine Medical Center, the home health agencies, Maine Center for Cancer Medicine, and the volunteer organization Hospice of Maine.
- Direct home hospice services were begun by HSM in 2004, after the process of transfer of three small existing home hospice programs of Community Health Services, SMMC Visiting Nurses and Visiting Nurse Services was completed. By reducing the number of organizations through integration, the fragmentation and duplication of services were also decreased. Hospice of Southern Maine, as an independent non-profit organization with a single focused mission, now could provide more efficient and cost-effective services for patients needing comprehensive end-of-life care.
- A needs assessment for a free-standing hospice facility and a fund raising feasibility study were both completed in 2003.
- A highly successful capital campaign was conducted 2003-2005, exceeded goals and raised $5.6 million in pledges from individuals, corporations, foundations, and state funds. This far surpassed any previous fundraising in the state for end of life care, reflecting the deep degree of community interest and support.
- Southern Maine previously had no inpatient hospice facility. Following the successful capital campaign, construction of the 18-bed Gosnell Memorial Hospice House began in Scarborough in 2005, and the facility opened its doors to patients in 2007.
- HSM began with a single employee in 2003, and numbered over 100 in 2009, including administrative and professional clinical staff. A seasoned and high quality healthcare management team was recruited to operate the organization.
- The all-volunteer group Hospice of Maine ceased operations at the end of 2005, and their trained volunteers were welcomed into HSM. All HSM Volunteers have undergone formal training of a minimum of 40 hours, and numbered approximately 150 in 2009.
- The home program growth steadily continued, with average daily census in 2009, at approximately 80-90 home program patients on service per day, with about 80% in private homes, and 20% in residential long term care. Home program visits in 2008, by nurse case managers, home health aides, social workers and chaplains totaled over 12,000 visits, driving over 200,000 miles across southern Maine.

- HSM also developed two special non-clinical programs. *A* "pre-hospice" program offering social work, chaplaincy and volunteer support for adult patients with life-limiting illness who wish to continue life-prolonging treatment. And a similar non-clinical pediatric family support program to assist families with children who have a prognosis of less than one year, but who are not formally enrolled in a hospice program.
- Providing educational opportunities to the professional community is a role taken seriously by HSM from its inception, and students, residents, and fellows from various disciplines and from various hospitals and university programs are welcomed. A formal monthly Continuing Medical Education program, with certification through Maine Medical Education Trust, was developed and open to all interested area physicians and providers.
- Financial stability was achieved, with an annual budget of over $7 million, with revenue coming primarily from Medicare, Medicaid and other commercial insurers for direct patient care services. Annual community fundraising grew to over $500 thousand per year, with these funds going toward under-insured patient care, community and professional education, volunteer programs, and bereavement programs open to the general community.

Much has been accomplished as Hospice of Southern Maine has grown and matured since those early days. Here is a snapshot of HSM today in 2016:

- Budget $11.5 million.
- Community fundraising supports 8% of the budget.
- Employees 157.
- Trained hospice volunteers 150.
- Patients served annually, approx 1500.
- Days of routine level care 93%
- Days of inpatient level care 6.8%.
- Average daily census routine 160 patients
- Average daily census in the hospice inpatient facility 14 patients.
- Average length of stay is 38 days; median length of stay is 10 days.
- Payor mix: Medicare 88%, Medicaid 3%, commercial 8%.
- Diagnoses: cancer 43%, heart disease 15%, lung disease 12%, dementia 7%, stroke 7%.
- Age over 65: 84%
- Medical staffing is through contract with Maine Medical Center, with most physicians having Hospice and Palliative Medicine board certification.
- Education is viewed as a core responsibility and there are many ongoing initiatives, both for professional and community education:
    - Professional education includes immersion experience for medical students; serving as a site for multiple area programs including for Palliative Care and Geriatric fellows, nursing students and nurse practitioner students, graduate students in social work, and for trainees in chaplaincy.
    - Education activities in the healthcare community and include "Hospice 101" in skilled nursing homes, training for hospital certified nursing assistants, grief training for nurses, ethics for social workers, symptom management for pharmacy students, and many other examples.

    - General community education offerings include an annual day-long conference featuring recognized experts as guest lecturers; discussion groups for seniors and caregivers on such topics as healthcare decision making, how to have an end of life conversation, and bereavement.
- Bereavement services for the family of enrolled patients is required by Medicare as part of the hospice benefit. HSM has a strong commitment to bereavement care and makes these services available at no charge to anyone in the community, whether their family member has been enrolled or not. Services offered include monthly support groups, individual counseling, monthly mailings on the progressive journey of grieving, healing through writing, art and music, collaborations with area senior centers and cancer community centers, and grief support for staff at nursing homes, homeless shelters and group homes.
- Spiritual care is required as part of the hospice benefit and HSM embraces this as an essential component of comprehensive care. There is a fulltime chaplaincy staff, experienced in end of life care. HSM chaplains are part of a network of community clergy so that resources for all religious faiths can be accessed. Community education for clergy is offered including introduction to hospice, and HSM is a training site for pastoral students. HSM chaplains on request often officiate at memorial services at no charge.

Can we apply lessons from this case study of Hospice of Southern Maine to help define and address the evolving challenges of the future? Can we apply our state experience to end of life care on a national level? We can generalize to some degree, such as 1) emphasizing the effectiveness of collaboration, 2) focusing on smooth transitions for patients as they move across the healthcare continuum, 3) preserving the culture of volunteerism and commitment to community that is embedded in most hospice programs, 4) realizing that regulation can be an impediment as well as a necessity, 5) that end of life care is an ethical imperative in any healthcare system.

After all of this work over 15 years, the access to and the quality of end of life care has clearly improved in Maine. Maine's rank among the states in hospice utilization has now risen from 49th to 28th. This is partly, but not solely, a result of the founding and growth of Hospice of Southern Maine.

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Over recent years there have been enormous strides made both nationally and on the state level. There have been professional advances, advances in public awareness, and an increased focus by state and federal governments.

Major professional advances include education of practitioners, in research, in development of standards of care, development of the formal medical specialty of Hospice and Palliative Medicine in 2006, development of palliative care services in hospitals, and increasing referral and utilization of hospice services.

Social attitudes are changing and there has been a huge leap in awareness of death and dying, end of life alternatives and choices, greater acceptance that ceasing curative care is not abandonment but rather a shift in the path of care. Popular writings on the subject are increasingly available. Writing such as Kubler-Ross's book On Death and Dying in 1969, was eye-opening to many; Bill Moyer's PBS series On Dyingin America covered these complex topics in an accessible and moving way; and Dr. Atul Gawande's recent book On Being Mortal has struck a chord and resonated with a wide audience. Clearly, the public wants to know and understand more, as the trajectories of aging and the burdens of chronic illness trend ever upward and eventually begin to everyone.

Over recent decades the way we die has changed in America. Most of us no longer die of short acute illnesses. We live longer and therefore more commonly suffer the debilitating consequences of aging. The advances of medicine enable us to live far longer with life-limiting illnesses, and we are often in very advanced stages of disease in our final phase of life. An apt quote from a 1997 Institute of Medicine report on Approaching Death: Improving Care at the End of Life, captures the benefit and the downside of modern medicine, "in some respects, this century's scientific and medical advances have made the living easier and the dying harder." Most of us do not die at home as we would prefer; most of us die in institutions of cancer, chronic illness, and increasingly of Alzheimer's Disease which is reaching epidemic proportions as life expectancy rises. In addition, the demographics of an aging population and social changes such as increasing mobility and fewer women at home translate into fewer family caregivers available to care for us when we are most vulnerable and need it most.

But not all is gloomy, all is not lost as life-limiting illness and age overtake us. These are challenges intrinsic to a progressive society in which many live to advanced age, and we are fortunate to enjoy the stability and prosperity we have. One has only to travel or work in a third world country to have no doubt about that. In 1900, life expectancy at birth was 47. In the U.S. it is 78, and if one lives to 65, it is 84. Many third world countries have life expectancies similar to ours in 1900.

There is no doubt that receiving a diagnosis of cancer or Alzheimer's Disease can be devastating and heartbreaking. But the picture is not entirely bleak and tragic. Yes, it may be an incurable illness, but it is not an untreatable illness. All is not lost and life does not end when the diagnosis is made. Life continues and there can be much still left to enjoy, there is still meaning in relationships. As the patient declines and care needs increase, there is love and honor in family care giving. It can bring satisfaction knowing that a loved ones days are more comfortable and secure. Illness and death need not be overwhelming and terrifying given the right support and care—it is after all, part of living.

But this task of caregiving can rarely be managed well without assistance. When the model of palliative and hospice care is adopted, with appropriate care and support, we can help alleviate symptoms, preserve dignity, enhance quality of life despite the disabilities, and enable families to continue their essential roles as caregivers. We can do this, we can ease the suffering and help guide the way for them.

Hospice is not a place or an agency, but rather a transportable model of care that accommodates the unique needs of a dying patient. Rather than aggressive, curative treatments that may be futile, as well as physically burdensome and painful for the dying patient, hospice care focuses on controlling pain, managing distressing physical symptoms, providing emotional and spiritual support, preserving personal dignity, respecting individual values, and offering social services and bereavement support for the patient's family members.

Ideally, patients receive in-home hospice care, relying on a family member as the primary caregiver, guided and supported by the interdisciplinary hospice team. For a majority of patients enrolled in hospice programs, it is indeed possible to die at home. However, the home setting is not a realistic option for a significant number of patients in advanced stages of illness in need of hospice services today. While in-home care will always be the preferred setting for most dying patients, it is critical that inpatient hospice care also be available for a variety of reasons:

- Family caregivers may not be available or capable of giving care at home – the patient may have no family, a spouse may be frail or elderly, other family and friends may be distant.
- Home care givers may need temporary respite from the intense demands of tiring round-the-clock care, or may need to take time to attend to other essential family needs for a short period.
- Some dying patients have no suitable home in which to reside at the end of life.
- After cessation of curative treatment in the hospital, family caregivers may need preparation and education prior to moving a dying family member from the hospital to home, with the hospice facility serving as a supportive interim setting.
- Patients at home may have periods in which pain and distressing symptoms become uncontrolled and will benefit from being stabilized in a hospice facility by staff who are experts in hospice and palliative care, with the goal of enabling the patient to move back home if possible.
- Some patients in advanced stages of illness require a higher level of medical and skilled nursing care to adequately control their pain and symptoms and meet their physical needs than can realistically be managed in the home setting.

It can be expected that the need for inpatient hospice care may increase as patients live longer with increasingly complex illnesses that are difficult to manage, and as caregivers are overwhelmed.

As we have noted, much progress has been made over recent years, but there are continuing as well as new challenges. In 1986 when the hospice benefit was permanently implemented as part of Medicare, it was an excellent example of a creative and effective framework that defined services, created the global payment structure that exists today, and enabled the hospice movement to grow and mature. But the rules as they were written then were more applicable to cancer diagnoses than to other life-limiting chronic illnesses, Alzheimer's disease, or the conditions of frail nursing home patients. The benefit periods and the clinical guidelines do not match these as well as for cancers which usually have a higher degree of predictability.

There are also the implications of social and demographic trends to consider, such as the circumstances and needs of caregivers caring for parents of very advanced age, who themselves may be aging and burdened with chronic illness.

Unlike in the 1980s, now palliative care services have been instituted in many hospitals, and the line between palliative care and hospice care is blurred. How are they alike and how are they different? The two types of care share the characteristics of: 1) multidisciplinary, integrated care, 2) the patient and the family are viewed as a unit and family support is an integral part of the care plan, and 3) intervention focuses on comfort and quality of life, not length of life.

The differences usually are that: 1) the timing of the services is different, with palliative care ideally incorporated much earlier in the course of illness and hospice in the final months or weeks of life, 2) palliative care services are often housed in hospitals, while hospice programs are usually community based and largely provide home services, 3) the Medicare structures are different with most palliative care reimbursed on a fee for service basis, while hospice is on a unique daily global payment system, 4) there are very specific criteria for patient eligibility for the hospice benefit, but not for palliative care, and 5) for hospices there are specifically defined requirements for the domains of care that mandate integrated holistic care of both patient and family, while palliative care does not have these regulatory requirements.

This hospice structure has worked well in the past with millions of patients and families receiving excellent end of life care, but is not working as well for many patients now.

- Should all curative or aggressive treatment have to be discontinued in order for patients to enroll in hospice programs?
- Should palliative treatments such as palliative radiation, interventional pain procedures, or inotropic infusions be allowed and paid for, the so-called “open access” concept?
- Should the payment period of 180 days be changed, or even eliminated, to better match diagnoses other than cancers?
- Should the per diem global payment be increased for patients with complex needs?
- Should other changes be made to the global payment, such as an increase for the first and last day?
- Can medical visits by advanced practice nurses or physician assistants, under the direction of the hospice medical director, be paid for in order to more efficiently utilize the physician resource?

Consideration of changes is due, and could go far to removing that bright line that now exists between palliative care and hospice care. Yet it would be unfortunate to alter the framework in such a way as to create unintended consequences that might erode the model of care. Hospice programs for many years have fostered a unique culture and care model that has stood the test of time and been a boon to millions of patients.

This committee is tasked with addressing issues of aging and serious illness, a daunting task. The converging challenges of an aging population, the predominance of chronic illnesses as the leading causes of death, and the cost of healthcare especially in the final months of life, create an exceedingly complex picture and solutions will be difficult to formulate. I thank you for your concern and diligence, and hope for your continuing support of the thousands of hospice programs around the nation.

A quote from a Hospice of Southern Maine family member:

Life is full of struggles and celebrations, pain and joy.
Death can be full of struggles, but few moments of joy and celebration.
Whether in one's home or in The Gosnell Memorial Hospice House, the care, support and understanding provided by Hospice of Southern Maine
helps to lighten the burden, free up moments of time and give relief and comfort to patients, families and friends.
All of which fosters personal enlightenment and intimate moments of celebration and joy to be part of this final rite of passage.
And quite frankly, it is those intimate moments of joy and celebration, shared with loved ones that gives peace to the dying and sustains the
living through the darkest moments of grief and loss.
Thank you.
A.G., daughter.

Historical Note:

"but what if no cure is possible and the end of life, as eventually it is for us all, is inevitable?... many people regret the time lost in inappropriate treatments aimed at an improbable cure when they have much to resolve in their relationships, as well as in their material affairs. A good death honors a whole life, and both charitable and government funds are being turned toward that end....It is important to be able to assist their journeys with both skill and compassion."

Dr. Cicely Saunders,
Founder of St.Christopher's Hospice, London.

Dr. Cicely Saunders, born in 1918 in England, educated at Oxford, a nurse in WWII, and later a physician, through her thoughtful and determined advocacy, defined and shaped the discipline of symptom control and supportive therapy for the most vulnerable of our populations, the dying. In 1967, by creating St. Christopher's Hospice in London as a place designed to care for the dying, she modeled a healthcare system where personhood and dignity were preserved, pain managed, and family-centered care provided. She is considered a major force in the development of modern hospice care throughout the world, produced considerable early research in opioid drug therapy in terminal patients, and was an early leader in the developing discipline that has come to be termed palliative care.

Saunders' efforts strongly influenced the American approach to the care of the dying. Florence Wald, from the Yale School of Nursing worked with Dr. Saunders and subsequently established the first hospice center in the United States in 1974 in Branford, Connecticut. There are now over 3100 hospice care programs, and payment for care is provided through a hospice Medicare benefit. The standards, domains of care, and emphasis on a patient and family centered approach are all modeled after Cecily Saunders' philosophy and principles of care, with an emphasis on quality of life rather than length of life.

Since then, there has been continual development and improvement of clinical standards of care, research, professional education, and consumer awareness of needs and choices related to end of life.

End of life issues will touch every family, and care of the dying should be a priority in an ethical and caring society. When life expectancy is six months or less, hospice provides a transportable model of care that accommodates the unique needs of an individual dying patient. Rather than aggressive, curative treatments that may be futile, as well as physically burdensome and painful for the dying patient, hospice care focuses on controlling pain, managing distressing physical symptoms, providing emotional and spiritual support, preserving personal dignity, respecting individual values, and offering social services and bereavement support for the patient's family members.

Volunteerism has been an integral part of hospice care and culture since the early days. In Maine, the first hospice organization established in the 1980s, was composed entirely of volunteers. Of note, Medicare conditions of participation for hospice uniquely mandate that at least 5% of patient contact hours be provided by trained hospice volunteers, of which there are now over 500,000 in the United States. The culture of volunteerism and community based initiatives resulted in most early hospice organizations being structured as non-profit organizations. That pattern has gradually shifted over recent years so that now for-profit organizations are beginning to predominate.

Approximately 2.5 million Americans die each year and about 25% currently receive hospice care in the last days of their lives. However, it is estimated that at least 40%, and likely more, of dying patients and their families could substantially benefit from hospice services.

In summary, hospice philosophy dictates three basic outcomes related to fundamental human values:

- Self-determined life closure
- Safe and comfortable dying
- Effective grieving

Achieving these outcomes incorporates these principles:

- affirms life and views dying as a normal part of life
- focuses on quality of life
- uses an interdisciplinary team approach to care that meets accepted professional standards
- neither hastens nor postpones death

- integrates physical, emotional, psychological, and spiritual aspects of care
- focuses on relief from suffering caused by pain and other distressing symptoms, rather than on treatment or cure of disease
- offers support to families and caregivers, treating the patient and family as a unit
- provides bereavement services to families for at least one year after the death of the patient
- Focus on healthcare ethics is particularly applicable to end of life care, and the principles include autonomy, justice, beneficence, and non-maleficence.