

# ***From the Start, Consider the Finish***

## **End-of-Life Care Historical Resource Guide**



### **MUSICAL CREATED BY**

Voices Theater in collaboration with Milwaukee Public Theatre

### **WITH SUPPORT FROM**

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## About The Resource Guide

This resource guide represents an overview of the literature on the cultural and historic issues regarding end-of-life care. In conjunction with the musical, *From the Start, Consider the Finish* and the post-performance talk-back sessions, we hope this resource guide will provide audience members with starting points for future reflection and support, including broader practical, historical and cultural perspectives on differing beliefs, attitudes and practices around death.

This section provides an introduction to the ***From the Start, Consider the Finish*** project and an overview of **historical responses to the need for end-of-life care in the U.S.** and references

## Introduction

Milwaukee Public Theatre received a major grant in 2011 from the Wisconsin Humanities Council to produce and tour *From the Start, Consider the Finish*, an original musical play that helps families begin the often challenging conversation about end-of-life planning. *From the Start, Consider the Finish*, presented by MPT in partnership with Voices Theater, tells real-life stories in a statewide tour of ten venues in September and October, 2011. Rogers Keene of Voices Theater adapted the play from an award-winning book, *The End of Life Advisor-Personal, Legal, and Medical Considerations for a Peaceful, Dignified Death* by Susan Dolan and Audrey Vizzard.

This project explores the importance of conversations about end-of-life care through the presentation of an original theatrework, post-show discussions, a Pocket Guide and this accompanying resource guide. This multi-faceted program is designed to engage family members and adult audiences through-out the state of Wisconsin in discussions focusing on issues raised by the play. The Resource Guides provide practical legal and medical information about local and national resources and more in-depth reflections on end-of-life care from diverse ethical, historical, philosophical and cultural points of view.

## About Us

**Milwaukee Public Theatre (MPT)** was founded in 1974 as Friends Mime Theatre. The name was changed in 1991 to better reflect their mission—to involve people of all ages, cultures, abilities/disabilities in the arts, covering a broad range of social issues that promote community healing. Each year MPT reaches over 100,000 people with original theatreworks, community celebrations and educational workshops. The Wisconsin Humanities Council (WHC) has partially funded three of their productions: *Ties that Bind* told the history of Wisconsin women from the 1830's to the 1920's; *Wisconsin Visions, Wisconsin Voices* was developed for Wisconsin's Sesquicentennial with stories of Native Americans, Latinos and African Americans and how they have shaped our State; and in 2009 and 2010 the WHC funded the initial research and tour of *Camp We-Kan-Tak-It*, a multi-media production based on camp newspapers of the Civilian Conservation Corps and the Works Progress Administration.

**Voices Theater**, under the direction of Rogers Keene of Medford, Wisconsin, collaborates with community groups and organizations by supporting their missions through the creation of original

theatreworks. Keene has a strong background in the humanities, with an M.S. in Curriculum and Instruction and a thesis on theater as an educational tool. Keene is also the playwright of *Now or Later?*, another play about end-of-life concerns that is still being performed in areas of Wisconsin. He based *From the Start, Consider the Finish*, on the American Journal of Nursing award-winning book *The End of Life Advisor; Personal, Legal and Medical Considerations for a Peaceful, Dignified Death* [2009 Kaplan] by Susan Dolan and Audrey Riker Vizzard.

**The collective mission of MPT and Voices Theatre** is to create theatreworks that reflect the social issues of our time in ways that stimulate meaningful thought for a deepened sense of place and community. Health has been a major theme in MPT's work since their inception. Voices Theatre has also had a strong interest in health issues.

## Historical Responses to End of Life Care in the U.S.

**Netting the Hospice Butterfly** (reprinted with permission of the author)

*Politics, Policy, and Translation of an Ideal*

**JOY BUCK, PhD, RN**

*This article presents a historical analysis of the American hospice movement. It examines the social and political factors that created an environment for the movement to emerge. It explores the processes by which multi-disciplinary teams came together to advance hospice as a necessary healthcare reform and the challenges they faced in doing so.*

In the late 1960s, a terminally ill patient with breast cancer elected to enter an interdisciplinary research study on care for the dying. Whereas the nurses and physicians on the research team managed her physical symptoms and psychological concerns, the priest helped her get her "spiritual house in order." He sat and listened to her as she spoke about her upbringing and helped her to realize her many accomplishments despite a deprived background. As life came to a close, the team supported her in her wish to die with dignity. Instead of going to the hospital, she chose to go out to dinner with her husband, children, and grandchildren and play poker until 1:00 AM (a favorite family game). Later that night, she died in peace, in her own bed in her own home (Wald, no date, p. 24). Within a year of her death, the research team, headed by Florence Wald, MS, RN, formed Hospice, Inc. one of the first modern hospice programs in the United States.

The hospice philosophy of care focuses on the art and science of pain and symptom management, emphasizing care provision within a broad framework that incorporates the physical, social, psychological, and spiritual realms of suffering. Ideally, hospice interdisciplinary care teams facilitate healing in the face of separation and loss, and help patients die comfortably at home surrounded by those who are most important to them. According to research, this is consistent with the wishes of 70% of Americans. Unfortunately, only 24.9% of Americans realize this wish (SUPPORT Principal Investigators, 1995).

Currently, more than one third of the dying spend their last days in an intensive care unit, and more than half of them die in moderate to severe pain. This article uses the development of the American hospice movement to explore the processes by which the hospice philosophy of care was integrated into the American healthcare system and the subsequent impact of this integration on the context of contemporary end-of-life care.

### Care for the Dying and the Call for Its Reform

During the 20th century, a combination of sociopolitical factors influenced the cause, manner, and location of dying. Until the early 1900s, care for the dying was firmly in the domain of home and family (Buhler-Wilkerson, 2001). Federal funding, especially after World War II, fueled medical and technological advances that could prolong life, but also disrupted the process of dying and the important role of family and religion in that process. The rise of medical centers, the quest for cure, population mobility, and women's work outside the home caused the location of dying to move from the home to the hospital. With that move, control over care decisions was transferred from the individual to the professional (Lerner, 1971; Starr, 1982). By the end of the 1950s, more than 60% of deaths were caused by cancer and chronic debilitating diseases, and 61% of these deaths occurred in the hospital. Sadly, the institutionalization of care for the dying had a profound impact on the experiences of dying patients and their families. Death often was seen as a sign of failure, and physicians rarely discussed terminal prognoses with patients. Believing it was in the patient's best interests, nurses and families joined the conspiracy of silence (Glaser & Strauss, 1965). Seminal research in sociology and nursing conducted during this era showed the stark realities of institutionalized dying.

Pain control was virtually nonexistent, and many people died in a room at the end of the hall, behind a closed door and alone (Duff & Hollingshead, 1968; Glaser & Strauss, 1968; Quint, 1967; Sudnow, 1967). These conditions also had severe implications for staff on units in which the death rate was high. Another study conducted in a cancer ward and published in *Time* magazine found that physicians and nurses considered the patient "walking dead," and patients constantly complained about "uncaring doctors," "unavailable" nurses, and experimental drugs they thought were being used on them as if they were guinea pigs ("Death in Cancer Ward," 1969, p. 56). Unfortunately, despite almost 60 years of medical and technological advances, needless suffering often accompanied dying for both the dying and the bereaved. In response to these conditions, Americans began to call for reform. The civil and women's rights, death-with-dignity, and consumer movements were foundational to a growing public discourse about the quality of life, patients' rights, and the role of informed consent in the medical system. In the case of hospice, idealistic grassroots reformers called for the release of dying patients from the social isolation of medical institutions and supported them as they returned home to the care of those most important to them. Legislators and others who advocated for the containment of healthcare costs soon joined idealistic reformers in their refrain for terminal care reform. Together, these strange bedfellows had the requisite social mass and political capital to effect change (Buck,

2004). It was within this context that the modern hospice movement was born, and British physician Cicely Saunders emerged as its charismatic leader.

### Cicely Saunders and the American Hospice Movement

Cicely Saunders' dedication to hospice began in the late 1940s and developed while she worked at St. Luke's Home for the Dying Poor and St. Joseph's Hospice for the Dying as a nurse, as a medical almoner (social worker), and finally as a physician (Clark, 2001; du Boulay, 1984). When she finished her medical training in the 1950s, she approached the Irish Sisters of Charity with a proposal to conduct clinical research at St. Joseph's. Although the research was necessary to validate the effectiveness of hospice care, Saunders' heart was directed to patient care. She admired the way the sisters remained sitting at the bedside to listen to patients and wrote of how they integrated care of the mind, body, and soul, and in doing so, transformed the wards there (Saunders, 1976).



**Cicely Saunders**

Their approach became central to her evolving understanding of care that focused on “being with” versus “doing to” and placed the needs of the patients and their families at the center of care. Building on this tradition of care, Saunders envisioned St. Christopher's, the hospice she hoped to build, as a community in which people shared the cost of being vulnerable. She embraced the belief that the dying have intrinsic value and are not inanimate receivers of care, but rather, active participants in their care. This philosophy broke down the artificial barriers between the social, physical, psychological, and spiritual components of care and blurred the boundaries of how health professionals and patients existed in relationship to each other (Clark, 1998, 2001, 2002; du Boulay, 1984). A charismatic leader and extremely successful at articulating the value of such care, Saunders soon became a powerful force in terminal care reform. In 1963, Saunders made the first of many trips to the United States to learn more about cancer care in America and to lecture about her work and research at St. Joseph's (Saunders, 1963). During these lectures, Saunders shared stories of dying patients who arrived at St. Joseph's expressing feelings of guilt, failure, and rejection. She showed slides of these patients at admission looking anxious and in pain, followed by views showing them in the last days of their lives looking comfortable, alert, and active. These images captured the good that can come from care that focuses on the alleviation of physical symptoms as well as on the social, psychological, and spiritual dimensions of suffering.

In telling the story of one hospice patient, Saunders illustrated how creating an environment that allowed patients to “be themselves” was a gift to both the dying and the bereaved. When the patient and his wife first entered St. Joseph's, they were both tense: he because he was in pain and she because she felt guilty that she would not be able to care for him until the end. The matron and medical officer welcomed them into the hospice and made them feel at home (Saunders, 1966). The patient was assured that his bed was his as long as he needed it, and his pain was quickly controlled by an analgesic mixture. In Saunders' (1966) words, *He was lying back in his bed filling in his football pools, an English form of gambling. This is really the way to help her; I couldn't take away the parting, but at least she could remember him like this.* (p. 16)

During this first visit, the seeds of the American hospice movement were sown, and a lasting and profound relationship between Saunders and Florence Wald was forged.

## The Hospice Midwife: Florence Wald and Hospice, Inc.

When Wald first heard Saunders speak in 1963, she was the Dean of the Yale School of Nursing and at a critical point in her life. During her tenure, she had grown increasingly concerned about the trend in medicine to focus on cure and technology rather than people (Wald, 1966). In search of a way to effect change, Wald believed that Saunders' conceptualization of hospice and the centrality of nursing within it offered the perfect vehicle by which she could achieve a "brave new world" in healthcare, with physicians and nurses as equals at the helm (Wald, 2000).

At Wald's invitation, Saunders returned to Yale in 1966 as the Annie Goodrich Visiting Professor of Nursing (Buck, 2005). This six-week visit culminated with the Institute on Care of the Terminally Ill, which brought together a multidisciplinary group of eminent thinkers and practitioners, including Elisabeth Kubler-Ross, to exchange information about death, dying, and bereavement. Over the next few years, correspondence among Saunders, Wald, and leaders in the emerging field of thanatology proliferated. The free exchange of ideas and research that ensued created a connectedness and synergy between these clinicians and scholars that transcended place and discipline (Clark, 2001; Foster & Corless, 1999). Thus, what would become an international hospice and palliative care movement was born.



**Florence Wald**

In 1968, Wald received funding from the United States Public Health Service Division of Nursing and the American Nurses Foundation to conduct the Nurse's Study of the Terminally Ill Patient and His Family, as well as the subsequent Interdisciplinary Study of the Dying Patient and his Family (Wald, 1970). As participant-observers, the research team documented the experiences of dying patients and their families as well as the reactions of their healthcare providers across care settings (Wald, 1970). These studies were foundational to the inception of the hospice movement in Connecticut. The studies served to coalesce and crystallize the group's vision for the creation of their hospice, but it also offered a vehicle by which they could work within a medical center to create individual and institutional change. Although the records show friction between the idealistic reformers and the status quo of a medical

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center, they also show that nurses, younger physicians, students, and others not firmly entrenched in the curative professional paradigm were more than willing to follow their lead (Buck, 2007). In 1971, a 15-member group, which included the research team, incorporated as Hospice, Inc.

Although Saunders continued to be an important advisor to the group, their hospice would have a distinctly American flair. The Board strategically selected task force members to work on a variety of committees based on expertise, professional and community stature, and other traits deemed important to organizational viability. Nursing was the most prominent profession represented, with clergy being second in the number of representatives. The dominance of the two professions reflected not only their genuine interest in terminal care reform, but also Wald's and Dobihal's effectiveness in energizing their base constituencies (Buck, 2005). Nurses came from schools of nursing, public health and home care, and area hospitals. The clerics came from a

variety of Christian and Jewish denominations. Within a year, the fledgling organization developed an organizational structure, and serious fund-raising efforts were under way.

The home care program opened in 1974, and the growing group spent countless hours raising community, professional, and political support for hospice (Lack & Buckingham, 1978). By the mid-1970s, hospice had struck a responsive chord in America, and new programs opened rapidly across the country. Similar to Hospice, Inc., many of these programs began as voluntary efforts and developed in accordance with the personal ideologies and professional paradigms of their founders as well as the environment in which they were created. They thus set the stage for considerable variability in the configuration and quality of the services provided. In an effort to standardize hospice, Connecticut hospice leaders copyrighted the term “hospice” and set strict criteria for its use. They then joined forces with leaders from Florida and other states to form the National Hospice Organization (NHO), now NHPKO (National Hospice and Palliative Care Organization), as a mechanism to secure reimbursement for hospice under the Medicare program (Beresford & Connor, 1999; Mor, Greer, & Kastenbaum, 1988; Seibold, 1992).

Congressional interest in hospice began in earnest during the mid-1970s. Many in Congress were concerned about the exponential growth of hospice and in 1978 called for an analysis of hospice organizations. The subsequent report identified that 59 organizations were providing at least one hospice type service and that another 73 organizations were in various stages of planning. There was wide variability in the configuration, type, and quality of services provided, and there was little evidence to substantiate claims that hospice was a superior model of care for the terminally ill (Government Accounting Office, 1979). To study hospice’s potential as a national program, Congress created a public/private partnership to fund and oversee the National Hospice Study, a research project to compare outcomes and cost data among patients receiving hospice care and standard care (Aiken & Marx, 1982; Mor et al., 1988).

While the National Hospice Study was underway, hospice advocates were busy crafting the Medicare hospice legislation and developing the requisite political support to ensure its enactment. Among the hospice community, there was considerable division about whether rapid integration into the American medical system was desirable or not. Nevertheless, several of NHO’s politically astute leaders mounted a campaign to achieve Medicare reimbursement for hospice. The Medicare hospice legislation was introduced by Representative Leon Panetta in 1980 and reintroduced in 1982. Congressional testimony shows that debates concerning the merits of the legislation were framed by four main constituencies: (1) the NHO leaders, who supported the bill; (2) the home health industry, which did not support the bill because they believed the benefit would result in increased competition and duplication of services; (3) legislators, some of whom were divided and some of whom were opposed for a variety of political and economic reasons; and (4) the Reagan administration, which argued against it because of its desire to rein the Medicare program in and the lack of conclusive cost data on hospice.

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In the end, hospice prevailed, and the legislation passed despite the conservative administration and well-reasoned arguments against the legislation's enactment. Whereas many celebrated the passage of the legislation, still others were concerned about how reimbursement would shape the context of hospice care. While promising to expand access to hospice care, the benefit also offered the opportunity for legislators to mold hospice into the prevailing template for reform. Capitated payment rates were set for comprehensive core services, and although volunteer and bereavement services were mandated, reimbursement to cover the cost of providing these services was not incorporated in the hospice rate. Eligibility criteria required that a patient be in the last 6 months of life, abandon all curative intensive treatment, and forfeit traditional Medicare benefits. In essence, this provision required patients to choose between life and death and left physicians with the difficult task of telling patients the truth about their condition and predicting when that death would occur (Buck, 2004). In the end, these provisions both decreased and increased access to hospice services and set the stage for many of the current challenges.

From the inception of the Medicare hospice benefit, the hospice industry has lobbied for the liberalization of eligibility criteria and increased per diem rates. Whereas the success of their lobbying efforts has eased the financial burden for hospice agencies, it has not always benefited hospice patients and their families. In the mid-1990s, Medicare eligibility requirements changed to allow beneficiaries to elect hospice care while retaining their traditional Medicare benefits for non-terminal diagnoses. Currently, hospice organizations are responsible to provide services related to a person's "terminal diagnosis," but not those related to coexisting "nonterminal diagnoses." Ostensibly, this policy change reduced the cost and care burdens of hospice organizations and allowed Medicare recipients more treatment options. Yet it also rendered people into their living and dying components, thus requiring them to navigate two different systems of care. For medically complex patients, delineating which disease and/or treatment is causing which symptom is problematic at best, if not impossible.



In addition, this division of the body into its nonterminal and terminal parts is confusing to patients and their caregivers. It can and does result in both physical and psychological harm. Increasingly, evidence of this harm and allegations of fraud and abuse are found in the popular press, health services research, and Congressional testimony (Buck, 2004). Whereas many hospices provide an invaluable service and remain true to their philosophical underpinnings, there continues to be wide variability in the type and quality of services provided by hospice across the country. At this juncture, it is critical that nurses keep the needs of patients and their families central to their efforts to improve systems of end-of-life care.

## Conclusion

Throughout history, society has been hindered in its efforts to improve the experience of dying patients and their families by a number of social, cultural, and political factors. As a reform movement, hospice cut across many boundaries and challenged assumptions about where care should be given, who should provide it, and who should be in control of the decisions surrounding that care. Yet, translating hospice into a reimbursable model of care without changing its nature or purpose proved to be a challenge, and

serious inadequacies remain in our models of end-of-life care. As a society, we continue to grapple with questions of how to shape and finance care for a growing population of chronically ill and medically frail elders. Whereas Medicare reform remains central to debates surrounding end-of-life care, the needs of terminally ill children and their families have yet to receive the legislative attention and support they deserve. As we move forward, it behooves us to examine the challenges we face critically, but to do so within the complex web of factors and forces that have shaped contemporary policy and practice. Such analyses are crucial to our ability to create systems of care that are responsive to the needs of the most vulnerable in our midst.

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