Private Conversations and Public Discourse

THE IMPORTANCE OF CONSUMER ENGAGEMENT IN END-OF-LIFE CARE
“MANKIND’S GREATEST GIFT, ALSO ITS GREATEST CURSE, IS THAT WE HAVE FREE CHOICE. WE CAN MAKE OUR CHOICES BUILT FROM LOVE OR FROM FEAR.”

ELISABETH KÜBLER-ROSS
ON DEATH AND DYING
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In Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-of-Life Care, the National Hospice and Palliative Care Organization (NHPCO) interweaves the stories of Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo with the 40-year history of the end-of-life care movement in the United States. These three poignant stories exemplify the difficult issues that many patients and their families face when making decisions about care at the end of life.

These stories also underscore the chilling fact that, despite advances in medical care, many Americans still suffer from unnecessary pain, discomfort and inadequate care at the end of life. For almost two decades, the Robert Wood Johnson Foundation helped lead a national movement to improve end-of-life care in the United States. We supported a three-pronged strategy to change patients’ and their families’ experiences at the end of life by helping to 1) educate and empower patients, families and caregivers; 2) train nurses, doctors and other health care providers to deliver better end-of-life and palliative care; and 3) make higher quality end-of-life care available in health care institutions.

During that time, end-of-life care in the United States improved substantially and became part of the health care mainstream. Patients and their families now have more and better information to help them manage care at the end of life, including the Five Wishes living will. Palliative care has also improved, in both extent and quality—offering better pain management and support options for patients at any age and any stage of their illness, and their families.

We take pride in knowing that we’ve helped build the end-of-life and palliative care fields, and we are pleased that the National Hospice and Palliative Care Organization is continuing to lead and mobilize the movement for improved care at the end of life. As this important report explains so convincingly, still more work is necessary to meet the physical, emotional and spiritual needs of patients and their families. And I hope that other individuals and organizations will recognize this truth and join together to help ensure that patients and families facing the end of life are able to experience the best care and greatest compassion that we can offer. They deserve nothing less.
INTRODUCTION

Everyone dies. It is inevitable. Yet talking about this experience, shared by all human-kind, is often difficult. Patients, families and health care professionals alike hesitate to discuss dying and death. The reasons for avoiding the conversations are numerous and complex.

Americans are notoriously adept at denying death’s inevitability. As members of a culture where youthfulness is accentuated, Americans have not been schooled in discussing issues associated with advanced illness, dying and grief.

Further, in some pockets of American cultures, merely talking about dying invites death to visit a patient or his/her family. Others may view discussions about dying as a sign of disrespect or insensitivity. And the historical pattern of health care inequities in the US complicates end-of-life care.

This discomfort—whether experienced as part of national consciousness or as a specific cultural norm—thwarts conversations between family members and between patients and clinicians about a person’s wishes at the end of life. And it is exacerbated by the complex and somewhat fragmented culture of medicine in the U.S.

In the 1950s and 60s, when medical technology seemed to be breaking new barriers every day to save and extend lives, life extension “at all costs” became an accepted norm of medical practice. As an unintended consequence, the needs of the dying were often ignored.

Generations of physicians have been taught to see death as the enemy, as something not to surrender to, no matter what. With an ever-expanding arsenal of tests and treatments at their disposal, physicians walk a fine line between “not giving up on their patients” and providing futile care. Many patients and their caregivers still rely on their doctors to decide what treatments to try and when, if ever, to acknowledge that the end of life is near. When clinicians stay unwaveringly intent on life-extending treatment, their conversations don’t transition to ones that focus on “quality of life”—the very things that allow a patient with advanced illness to enjoy what life has to offer, whether it be spending time with family and friends, decreasing pain, or receiving needed emotional and spiritual support.

Advances have occurred over the past 40 years, as a growing group of consumers, health care providers, social change leaders, politicians, insurers, philanthropists and the media has worked to change public perceptions about dying and to improve the care and quality of life for those facing advanced illness, death and grief. This report explores many of these consumer engagement and public awareness efforts. Despite this progress, however, much...
more work is needed to assure that all Americans are able to reliably receive high-quality care, in accordance with their preferences, as they confront illness and the end of life.

THE NEED FOR CHANGE

The convergence of several variables demands renewed attention to the quest to inform and engage consumers in end of life issues: the graying of America, continued lack of understanding of patient preferences at life’s end, and a changing political climate in relation to health care.

Today, seven out of 10 Americans die from chronic disease. Data on the number of Americans living with advanced illness and needing care is also staggering—and will continue to confound health care delivery in the foreseeable future. Over the next 25 years, the number of Americans living with a chronic illness is expected to double with the aging of the baby boomers. By 2020, the number of people living with at least one chronic illness will increase to 157 million. Half of Americans still die in hospitals, despite numerous studies revealing a preference for dying at home.

The impact of these demographic statistics grows exponentially when caregivers are considered. One American in five provides care for another adult, often a family member. There are currently an estimated 44 million caregivers in the United States—and, according to the U.S. Census Bureau, that number is expected to surge as today’s baby boomers age. Studies show that caregivers are less healthy than those not involved in caring for others, and are at risk for compromising their own physical, psychological, spiritual and financial wellbeing.

The Agency for Healthcare Research and Quality (AHRQ) Research in Action Issue 12: Advance Care Planning Preferences for Care at the End of Life synthesized findings from AHRQ-sponsored studies on advance care planning in March 2003. Highlights of AHRQ research as quoted from the Research in Action website reveal that:

- Less than 50 percent of the severely or terminally ill patients studied had an advance directive in their medical record.
- Only 12 percent of patients with an advance directive had received input from their physician in its development.
- Between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed.
- Language in advance directives was usually too nonspecific and general to provide clear instruction.
- Surrogates named in the advance directive often were not present to make decisions or were too emotionally overwrought to offer guidance.

These statistics are not just numbers; they represent real people whose lives—and deaths—are impacted by the hard choices they make with loved ones and with their clinicians about their care. The heartbreaking stories of Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo exemplify the difficult issues that patients and families face when confronting illness and making decisions about care. We present their stories—and the importance of open dialogue on end-of-life issues—in this report.

The data compellingly suggests that in contemporary American society, issues surrounding death and dying are public health issues, requiring public response. Public discourse is often contentious as our nation grapples with topics such as the right to die and physician-aided suicide. This was obvious in the 1970s, 1980s and 1990s with the Quinlan, Cruzan and Schiavo cases. And the ‘death panel’ discussion that erupted in 2009 and 2010 preceding the passage of the Patient Protection and Affordable Care Act is evidence of how confusing our national dialogue on end-of-life issues remains.

The pervasive denial of death, combined with baby boomer demographics and ongoing changes as America’s health care reform unfolds, means that the task of improving care for those in the last years of life remains one of society’s biggest challenges. Renewed efforts need to be undertaken that normalize conversations, raise awareness and change behavior.
This report provides a retrospective glance at 40 years of public engagement in end-of-life issues and highlights these key points:

- In each decade, there have been individuals and situations that have elevated end-of-life issues to the forefront of popular culture and national attention.
- There is a common thread of responsibility—societal and individual—that runs through each decade.
- There is consensus among those working on these issues that society has not yet reached the “tipping point” where attention to the final phase of life has become an integral part of all health care planning and decision-making in this country.

This report is a call to action, a rallying cry that encourages—and provides a framework for—a national agenda for consumer engagement in end-of-life issues. The information in this report is designed to serve as a catalyst for more individuals and organizations to assume the mantle of responsibility for improving the way society cares for people in the final months and years of life.
WHAT IS END-OF-LIFE CARE?

As the nation’s oldest and largest organization focused exclusively on end-of-life care, the National Hospice and Palliative Care Organization (NHPCO) in its efforts to lead and mobilize social change for improved care at the end of life, defines “end-of-life care” as:

Encompassing the interdisciplinary care and supportive services provided to seriously ill people and their family caregivers focused on alleviating suffering, facilitating end-of-life wishes, training family caregivers and providing support to the bereaved.

End-of-life care is a component of palliative care. NHPCO’s Standards of Practice for Hospice Programs describe palliative care as:

Treatment that enhances comfort and improves the quality of an individual’s life during the last phase of life. No specific therapy is excluded from consideration. The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals rather than affect the underlying disease. An individual’s needs must continue to be assessed and all treatment options explored and evaluated in the context of an individual’s values and symptoms. The individual’s choices and decisions regarding care are paramount and must be followed.

In the United States, hospice and palliative care are recognized as the “gold standard” in the provision of end-of-life care. End-of-life care also extends beyond the death of a loved one, as family and friends work through the grieving process.

NO SINGLE LABEL FOR END-OF-LIFE CARE

End-of-life care isn’t one single thing. It’s offered by many types of providers, and it’s offered in many different settings. The provision of end-of-life care varies and can “look” very different in communities across the country. In Florida, a person might receive services from a PACE program (Program for All-Inclusive Care for the Elderly) that is run by a hospice while, in another state, a person may find 25 hospices that all provide essentially the same services. Some hospitals have thriving palliative care teams or their own hospice...
programs, while others discharge patients without any discussion about hospice or palliative care. Still other hospitals—and some hospices—have robust pediatric palliative care programs, while others have no staff formally trained to address the unique needs of dying children and their family caregivers. Care in skilled nursing facilities can also vary—one facility may have contracts with several local hospice and palliative care providers while another in the same community may rely solely on its own staff to serve dying residents.

"Where" end-of-life care is provided also varies, depending on the place the person calls “home.” For example, care might be provided in a patient’s or family member’s home, in a hospital or nursing home, in a VA or correctional facility, in a hospice residential facility, or for the homeless person, on the street or in a shelter.

**ADVANCE CARE PLANNING**

Yet, to adequately understand end-of-life care, one must look beyond the process of dying and include the process of identifying, discussing and documenting wishes for care during the last days, weeks or months of life. Ideally this process of advance care planning happens throughout a lifetime so that, in the event of a medical crisis, family caregivers and physicians can ensure that wishes are honored.

**THE EVOLUTION OF END-OF-LIFE CARE IN THE UNITED STATES**

Attention to end of life in the US began in the early 1970s when a group of committed individuals organized to start the nation’s first hospice. The Connecticut Hospice opened its doors in 1974, just seven years after Dame Cicely Saunders founded the first modern hospice outside of London. Since then, the growth of the hospice and palliative care movement has been unprecedented. Passage of the Medicare Hospice Benefit in 1982 as part of the Tax Equity and Fiscal Responsibility Act solidified the role of hospice as a provider of end-of-life care; there are now more than 4,800 hospices providing care to an estimated 1.45 million patients annually. In 2006, the American Board of Medical Specialties approved subspecialty status for hospice and palliative medicine. 2009 data shows more than 2,800 physicians, 11,200 nurses and almost 400 nurse practitioners are now board certified in palliative care.

The SUPPORT study fueled the field of end-of-life care, prompting new research and spawning new programs that sought to improve information on what patients and their families value when confronting advanced illness. The graphic on the following page illustrates the evolution of efforts within the context of important consumer/community engagement initiatives. Please visit www.nhpco.org to view a timeline that touches on factors in the past 40-plus years that have influenced public perception of end-of-life care. View an in-depth timeline of sentinel events from the 1970s through 2010 that have influenced public perceptions of end-of-life care in the Appendix of this report on page 34.

Over the next 25 years, the number of Americans living with a chronic illness is expected to double.
HOSPICE FACTS AND FIGURES

During this 40-year history, hospice has been the primary delivery mechanism for end-of-life care. As described by NHPCO’s Caring Connections program, hospice care is predicated on the belief that each of us has the right to die pain-free and with grace, and that our loved ones should receive the necessary support to allow us to do so:

- Hospice focuses on caring, not curing—with care most often provided in the person’s home.
- Hospice care also is provided in freestanding hospice centers, hospitals and nursing homes, and in other long-term care facilities.

• Hospice services are available to patients of any age, religion, race or illness.
• Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs and other managed care organizations.

NUMBER OF PATIENTS RECEIVING HOSPICE CARE IS GROWING

Between 2000 and 2009, the number of patients served by the nation’s 4,800 hospices doubled. NHPCO estimates that 41.6 percent of all who die in the U.S. receive care from a hospice program.

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<tr>
<th>PRIMARY DIAGNOSIS</th>
<th>% OF HOSPICE PATIENTS</th>
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<tbody>
<tr>
<td>Cancer</td>
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<td>Debility Unspecified</td>
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<td>Heart Disease</td>
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<td>Dementia</td>
<td>11.2 percent</td>
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<tr>
<td>Lung Disease</td>
<td>8.2 percent</td>
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AVERAGE LENGTH OF SERVICE HAS DECREASED

The average number of days of care—or average length of service—for hospice patients decreased from 69.5 days in 2008 to 69.0 in 2009. While many patients receive hospice care for months approximately 34.4% of hospice patients received care for seven days or less—often an insufficient time for patients and families to benefit from the full scope of medical and psychosocial services that hospice care offers.

AGE AND GENDER

In 2009, people age 75 and older accounted for 53.8 percent of hospice patients. Overall, more women received care than men, with women accounting for 56.6 percent of patients. As the U.S. population ages, the number of Americans receiving hospice care will also increase.

TOP FIVE DIAGNOSES

It was once true that hospices served cancer patients almost exclusively—but those days are long since passed. Hospice is reaching out to care for people with a broader range of diagnoses, as NHPCO 2009 data show:
The growth in hospice and palliative care over the last 40 years has been punctuated with several events that highlight the need for public discourse, most notably the stories of three young women: Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo. Unwittingly, these three women were instrumental in shaping public opinion on the emotionally-charged and complex issue of the “right to die.” As a result of their tragic deaths, they compelled our legal system to develop relevant laws to protect our rights and opened America’s eyes to the limitations of the law and the importance of documenting personal end-of-life preferences.

On the one hand, their stories are surprisingly similar. These young women were placed on artificial life support to prolong their lives following either an accident or illness that left them permanently unconscious—or in a “persistent vegetative state.” After a period of time, each woman’s legal guardian sought to discontinue the medical intervention, engaging in legal battles to do what each felt their loved one would have wanted.

What is different is the decade in which each case occurred—and the medical advancements, media...
coverage and public perceptions at the time that impacted the course of the legal battles as well as each woman's final days.

1975: KAREN ANN QUINLAN

At the age of 21, Karen Ann Quinlan lost consciousness while at a party and was rushed to the emergency room of a local hospital in Newton, New Jersey. When her parents arrived on the scene, their daughter had lapsed into a coma and was placed on artificial life support—both a respirator and a nasogastric tube for artificial nutrition and hydration. After several months of waiting and hoping for a change in medical status, Quinlan’s parents asked the hospital to turn off the respirator and allow their daughter to die in peace. The hospital refused, on the grounds that doing so was immoral. “You have to understand our position,” the hospital administrator told Quinlan’s father, “in this hospital, we don’t kill people.”

This was 1975—a time when advancements in the medical community were helping to save and extend lives. The first direct-current defibrillator had been invented in 1961, followed by the establishment of the first hospital coronary care unit; the 911 emergency system had been launched in 1968; and the first school program to train ambulance attendants in CPR had begun in 1969. What’s more, medicine had only just named the condition to which Quinlan had fallen victim—the persistent vegetative state—in 1973. The medical community and the American public were still very much enraptured by such advancements and wanted to do “everything possible.” No one was yet prepared to deal with the negative repercussions of these advancements.

Following a legal battle with Quinlan’s physician and the state attorney general, the case was brought before the New Jersey Supreme Court in 1976. The court ruled that Quinlan had a constitutional right to privacy that her father could exercise on her behalf. While the court granted him the right to discontinue all life support, Quinlan’s father chose only to wean her off the respirator. To the medical community’s surprise, she started breathing on her own. Quinlan lived on in a persistent vegetative state, kept alive with artificial nutrition and hydration, and died from pneumonia 10 years later.

The Quinlan case paved the way for several proactive steps in this still unfamiliar, uncharted territory. The U.S. Congress established a President’s Commission to examine the ethical issues arising from advancements in medicine and published two reports by 1983: Defining Death and Deciding to Forego Life-Sustaining Treatment. More notably, the California Legislature passed the nation’s first living will law to protect a person’s rights concerning his/her medical treatment. The first living will document was created in 1969 and was followed by three failed attempts to pass living will laws in Florida and California. It took the Quinlan case—and public interest in the issue—for the law to pass in California. While other states followed suit, state living will laws varied in their provisions, resulting in a fragmented national ethos. In Missouri, for example, feeding tubes were excluded from medical technology considered medical treatment—the very issue that forced Nancy Cruzan’s parents to wage a four-year legal battle.

1983: NANCY CRUZAN

In 1983, 25-year old Nancy Cruzan swerved off the road and was thrown from her car while en route to her parent’s home in Carthage, Missouri. Paramedics found her with no vital signs, but they were
able to resuscitate her. By the time she reached the hospital, she had fallen into a deep coma. After several weeks of hospitalization, she was diagnosed, like Quinlan eight years before, as being in a persistent vegetative state. As a result of the accident, Cruzan had suffered anoxia, or lack of oxygen to the brain, that caused her bodily functions to shut down. She was placed on a respirator until hospital staff was able to get her to breathe on her own. Because she could not eat or drink, surgeons inserted a feeding tube.

For several years, her family waited in vain for any signs of recovery. Then, in 1986, they asked medical officials to remove her feeding tube after they jointly agreed that’s what she would have wanted. The medical officials refused to comply unless a specific Order of the Courts of Missouri was furnished. The family’s request was at odds with the Missouri living will law that had been enacted following the Quinlan case.

After battling with the medical establishment, the Cruzan case was brought before the Missouri Supreme Court in 1988. The Court found that unless Cruzan had left clear instruction or convincing evidence that she did not want a feeding tube, it could not be removed. In 1989, the U.S. Supreme Court agreed to hear the case, marking the first right-to-die case to reach the hallowed chambers. The case generated national headlines and captured public attention for the next 18 months. On June 25, 1990, in a 5-4 decision, the Cruzan family lost the case: the federal court stated that the Missouri ruling did not violate the federal constitution and, “unless Nancy Cruzan had left clear and convincing evidence of her wish to remove the feeding tube, it had to stay in place.” Ultimately, the Cruzan family prevailed when two witnesses came forward, testifying that Nancy had indeed expressed those wishes during conversations with each of them. On December 15, 1990, the tube was removed. Nancy Cruzan died 11 days later.

While the Cruzans were finishing their long journey of caring for Nancy, the ordeal of Terri Schiavo’s family was just beginning.

1990: TERRI SCHIAVO

On the morning of February 25, 1990, 26-year-old Terri Schiavo collapsed in the hallway of her apartment in St. Petersburg, Florida. Her husband, Michael, dialed 911. By the time the paramedics arrived, she was not breathing and had no pulse. They attempted to resuscitate her: she was defibrillated several times and was hospitalized, placed on a respirator and had a feeding tube inserted. The long period without oxygen led to profound brain injury that eventually, upon autopsy, was termed “anoxic-ischemic encephalopathy,” a disorder characterized by a reduction in oxygen supply combined with reduced blood flow to the brain.

While Terri’s medical condition turned out to be very similar to that of Nancy Cruzan’s, the Schiavo family disagreed on what they perceived to be her true cognitive state and on whether she would have wanted her life prolonged through artificial means. Terri’s husband believed she was in a permanent vegetative state and would not have wanted artificial means to prolong her life. Conversely, Terri’s parents and siblings were convinced that she was in a “minimally conscious state” and that removing her life support was tantamount to murder. The ensuing initial legal battles between 1993 and 2000 involved the husband’s role as legal guardian and his request, beginning in 1998, to remove Terri’s life support.

“MAKE A LIVING WILL. TALK ABOUT IT. DEATH IS GOING TO HAPPEN TO EVERYBODY. WRITE IT DOWN. EVEN IF YOU WRITE IT ON A PIECE OF PAPER AT HOME AND HAVE YOUR FAMILY WITNESS IT, YOU NEED TO WRITE IT DOWN.”

MICHAEL SCHIAVO
In 2000, the case changed dramatically when the media entered the picture: a lone reporter from the *St. Petersburg Times* was assigned to the case and seated in the courtroom. While Michael Schiavo’s attorney objected to the reporter’s presence, the judge ruled to permit the media coverage, absent of any case law to support doing otherwise. It is worth noting that the judge had offered an extended recess to allow both attorneys to research the issue, but both decided to proceed. 3

With the advent of 24-hour cable television, the local story soon reached epic proportions, transforming a personal legal matter into national tabloid news. The coverage incited demonstrations among pro-life and disability rights activists and prompted politicians, including then-Florida Governor Jeb Bush and House Majority Leader Tom Delay, to take unprecedented moves to pass legislation granting Terri’s parents more time to argue their case.

In 2000, the judge ruled that Michael Schiavo could stop tube feeding Terri and allow her to die. Shortly after this decision, Michael had Terri moved from a nursing facility to Woodside, a residential facility operated by The Hospice of the Florida Suncoast (now Suncoast Hospice). On April 24, 2001, Terri’s artificial nutrition and hydration was stopped—but not for long; Terri’s parents filed a new lawsuit, leading to an emergency order to resume feeding.

In all, the Schiavo case involved 14 appeals and numerous motions, petitions and hearings in the Florida courts; five suits in federal district court; Florida legislation known as “Terri’s Law” (later struck down by the Supreme Court of Florida); and the fast-track passage of the federal law, “For the relief of the parents of Theresa Marie Schiavo,” sponsored by House Majority Leader Tom Delay. Ultimately, the decision to discontinue life support fell back to the Florida courts, which ruled in favor of her husband. On March 18, 2005, Terri was disconnected from life support. She died on March 31.

During the final weeks of Schiavo’s life, media attention to the story, fueled by around-the-clock protestors outside Woodside, resulted in unprecedented attention to the issue of advance care planning. During the week before Terri Schiavo’s death, NHPCO received hundreds of phone calls each day – including more than 1,200 in a single day – as well as thousands of emails and web hits from people seeking advance directives.”

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NATIONAL ATTENTION TO HONORING END-OF-LIFE DECISIONS

In the early 1990s, leaders at the Robert Wood Johnson Foundation (RWJF) became alarmed that patients near the end of life were being subjected to high-tech and high-cost interventions that were ineffective and contrary to their preferences. With the goal of decreasing suffering, RWJF staff engaged leading medical researchers in the development and implementation of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). Prior to the 1995 publication of the SUPPORT study, research about end-of-life care preferences and treatment decisions was scarce.

The five-year study was conducted in two phases. The first phase focused on describing the prognoses and preferences of patients admitted to five major medical centers with one or more of nine life-threatening diagnoses. Phase I confirmed the hypothesis that a majority of patients received care that was ineffective and against the wishes of the patient and/or family. Phase I also revealed that physicians seldom consulted prognosis data or asked about preferences prior to determining the plan of care. Furthermore, Phase I showed that patients and their families were ill-equipped to understand their options or to articulate their preferences. Using models for prognosis developed in Phase I, the second phase of the study evaluated the outcomes of three interventions designed to improve prognostication and communication about prognosis and preferences:

- Validated prognostic models were developed for each patient so that physicians could estimate the likelihood of severe disability or death.
- Specially-trained nurses talked with patients and their families to understand their wishes and relay them to the physicians and nurses involved in their care.
- Physicians received detailed written instructions about patients and families’ wishes regarding treatment.

RWJF expected the three interventions to be effective in promoting quality of life and changing the landscape of end-of-life care in the United States. It was not to be. The interventions failed to achieve improvements in the timing of Do-Not-Resuscitate (DNR) orders; patient/family and physician agreement regarding DNR; reduction of time spent in the intensive care unit or on a ventilator; and pain management or resource use for patients with advanced illness.

However, the study was highly successful in illuminating the need for changes in social and professional norms and priorities. The results of SUPPORT raised the salience of end-of-life care issues among health care providers, employers and funders and catalyzed more than a decade of initiatives to improve end-of-life care.

These initiatives took many different forms, capitalizing on existing leverage points and approaching improvement from several angles. The overarching goals were to:

- Understand consumer concerns and increase awareness of options for care and control;
- Build a supportive environment—legally and culturally—for patient-focused, value-directed care;
- Increase clinical capacity for quality end-of-life care (e.g., train more clinicians to address the unique clinical and non-clinical issues of care at the end of life); and
- Develop successful models for delivery of high quality end-of-life care.

Many of the initiatives focused directly on consumer outreach, education and/or engagement, while others included consumer-directed components.
AMERICANS FROM DIVERSE BACKGROUNDS SAY THEY WANT THE SAME THING: A HUMANE, COMPASSIONATE PROCESS FOR DYING.
Learning What Consumers Want and Need

The Quest to Die with Dignity: an Analysis of Americans’ Values, Opinions and Attitudes Concerning End-of-Life Care was funded by RWJF and published in 1997. Researchers gathered information via focus groups involving 385 people who were not necessarily sick or dying and follow-up interviews with people who were terminally ill or had experienced the recent death of a loved one. The report’s authors commented on the “remarkable degree” to which participants of different ages, races and cultural backgrounds shared the same opinions, values, fears, beliefs and hopes about end-of-life care and dying. Focus group participants:

- Feared they would die connected to tubes and machines, in direct contrast to their desire for a natural death, surrounded by family or loved ones;
- Had little or no confidence that the current health care system could or would support them in dying how they wished;
- Believed that planning for their care at the end of life was important, but they preferred to avoid talking about it;
- Did not “want to be a burden”—family concerns drove their decisions about care at the end of life.

The report concluded that, “Americans from diverse backgrounds say they want the same thing: a humane, compassionate process for dying that allows them as much control as possible over what happens at the end of their lives.”

From the Quest to Die with Dignity study came 10 suggestions for improving the process of dying in America. Seven of these addressed advance care planning, recommending:

- Increased public dialogue to motivate advance care planning;
- Facilitation of communication between physicians and consumers to improve the doctor-patient relationship and develop a shared language for discussions;
- Provision of information to help consumers make more responsible care decisions;
- Development of better advance directive documents that address the range of options consumers may face when dying;
- Physician training to acknowledge and act on wishes expressed by family members;
- Possible use of incentives, such as lower insurance premiums, to motivate more Americans to put their wishes into writing;
- Respect for cultural and religious values and practices surrounding death and dying.

Many consumer outreach initiatives developed in subsequent years addressed these suggestions.

Participants feared they would die connected to tubes and machines, in contrast to their desire for a natural death, surrounded by family or loved ones.
“THE ULTIMATE LESSON ALL OF US HAVE TO LEARN IS UNCONDITIONAL LOVE, WHICH INCLUDES NOT ONLY OTHERS, BUT OURSELVES AS WELL. ”

ELISABETH KÜBLER-ROSS
ON DEATH AND DYING
CONSUMER OUTREACH, EDUCATION AND ENGAGEMENT

Some of the earliest efforts to empower consumers to shape and demand better end-of-life care started at the national level. Americans for Better Care of the Dying (ABCD) was founded as an independent non-profit “consumer membership” organization in 1997 in Washington, D.C. with a goal of assuring quality end-of-life care.

The organization aimed to build momentum for reform; explore new methods and systems for delivering care; and shape public policy through evidence-based understanding. ABCD recruited consumers to join a grassroots effort to improve care by bringing pressure on policymakers and health care provider organizations. Leaders of the organization also published a consumer guide to end-of-life issues, A Handbook for Mortals. Ultimately, the organization struggled to obtain adequate financial support from consumer members and other funders and, as a result, the ABCD board of directors closed the organization in 2007.

In 1998, Partnership for Caring: America’s Voices for the Dying (PFC) was founded in Washington, D.C. PFC evolved from an organization called “Choice in Dying” and focused on facilitating advance care planning through completion of living wills and/or health care surrogate designations. The partnership brought together representatives of organizations and initiatives across the country. Of particular note was the partnership with the American Bar Association’s (ABA) Committee on Elder Affairs. With ABA’s help, PFC published a yearly summary of state legislation affecting advance care planning and ranked each state’s efforts based on how well the laws supported consumer choice and delivery of preference-based health care.

In April 1999, RWJF established a national program office at PFC for its national initiative, Last Acts. The Last Acts initiative brought together a national-level coalition of more than 800 health and consumer groups to (1) improve communication and decision-making for consumers about their own deaths, (2) change the culture of health care institutions and (3) change American culture and attitudes toward death. In an effort to ensure the sustainability of Last Acts at the conclusion of RWJF’s funding commitment, PFC and Last Acts became the Last Acts Partnership. When the organization closed in 2004, the majority of its assets were acquired by the National Hospice and Palliative Care Organization (NHPCO) and, with funding from RWJF, Caring Connections was born.

One of the most visible Last Acts initiatives was the report, Means
to a Better End (MTBE), which was published in November 2002. Designed to “…spark public discussion about the state of dying in America…”, the report rated 50 states and the District of Columbia on eight criteria affecting end-of-life care and showed that, for the most part, care was mediocre. It also highlighted the lack of data available on other criteria that significantly affect access to quality care for the dying.

By profiling end-of-life care strengths and weaknesses, the MTBE report provided both the impetus and a framework for improvement. In addition, it was unique in targeting a public rather than professional audience. The breadth of coverage about MTBE in national publications and newspapers suggests that it helped raise public awareness about the salient issues surrounding end-of-life care.

Aging with Dignity also formed in the late 1990s, with the primary purpose to “affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end of life.” In 1997, the organization published the Five Wishes living will, the first “user-friendly” living will designed to help people articulate their preferences for end-of-life care in the context of five specific elements of care – health care decisions, medical treatment, physical comfort, social interactions and messages to family. The popular Five Wishes document, which meets the legal requirements for living wills in 42 states, is now available in 23 languages, with more than 12 million copies in circulation across the nation.

While the national campaigns and initiatives brought together key partners and crafted consistent messages for consumers, health care is controlled primarily at the state level and ultimately delivered at the local level. Consequently, state-level initiatives began that were dedicated to reaching consumers where they live by changing social norms and public policy, as well as increasing discussions between consumers and their health care providers.

Nearly all the projects that received funding from CSP engaged their communities or states through focus groups, forums, community discussions and surveys. The most successful projects focused on community education of target audiences that were “primed” to receive it, such as older individuals and current or future caregivers (mostly women age 40 and older). Examples of successful initiatives included:

- The Utah-based Dialogue in Action project, which brought together small groups of health care professionals and consumers to share end-of-life care experiences and discuss systematic improvement;
- Educational training on the Medicare Hospice Benefit for Minnesota-based insurance counselors; and

The Community State Partnerships to Improve End-of-Life Care (CSP), a national program of RWJF based at The Center for Practical Bioethics (formally the Midwest Bioethics Center) in Kansas City, Missouri, provided grant funding and technical assistance to public-private partnerships composed of providers, academic institutions, insurers and policy makers in 23 states from 1999-2003. The program had four primary goals: to remove barriers to good end-of-life care; to develop policies and implement practices that promote excellence; to create public understanding about care choices; and to monitor the impact of these efforts.
• Educational training on end-of-life care for all of Kansas’ county agricultural agents—a central source of information in rural counties.

Many of the CSP projects discovered that local community coalitions, whose members understood the norms and values of local consumers, were essential in identifying and reaching an audience that could be engaged in change efforts. These local groups performed best when they identified with a larger effort and when they could rally around a state or national event. Events provided coalitions with a reason to meet, a focus for their work and momentum for growth, as well as credible information to share and tools for action.

Other influential activities included national media events and local coalitions that engaged individuals in social change efforts. In September 2000, the four-part public television series, On Our Own Terms (OOT), was broadcast nationwide and examined the cultural, medical, ethical and spiritual aspects of death and dying in America. The series was directed by Bill and Judith Moyers of Public Affairs Television, Inc., and was funded by grants from RWJF, the Fetzer Institute, the Nathan Cummings Foundation, the Kohlberg Foundation, Inc., the Laurance S. Rockefeller Fund and Mutual of America Life Insurance Company. As RWJF stated in a January 1999 press release, the series was intended to show the progress and problems in delivering high-quality end-of-life care and to “give the public the language and opportunity to talk about an issue that too often remains taboo.”

In conjunction with the OOOT series, Last Acts conducted a year-long outreach campaign to connect public television stations, healthcare professionals and institutions, civic organizations, community-based groups and individuals and to encourage them to use this series to catalyze dialogue and community action on end-of-life issues. Local coalitions were intended to be the workhorses of the outreach and were furnished with a range of OOOT tools and materials to help: a leadership guide; community awards for public television station community outreach; a leadership-training videoconference; a discussion guide for individuals, families and groups; a website; and an electronic outreach newsletter.

In addition, a multi-faceted project, Finding Our Way: Living with
Dying in America (FOW), was conducted between 2000 and 2002. It included a 15-part newspaper series, community outreach via local coalitions, and Internet-based learning. The newspaper series, published in fall of 2001, was designed to educate consumers about issues and opportunities for managing care at the end of life. The community outreach initiative, which started in the late spring of 2001 and continued into 2002, sought to increase the series’ readership as well as its impact on readers. To evaluate the project, surveys and interviews were conducted to assess the project’s success, access, satisfaction, outreach and impact. Newspaper editors, local end-of-life coalition leaders and readers/consumers were all included in this evaluation process.

Following these two successful local community outreach programs, RWJF announced the Rallying Points (RP) initiative. Designed as an adjunct to Last Acts and directed by Partnership for Caring, Rallying Points aimed to mobilize improvement of end-of-life care at the grassroots community level, building on 305 local and state coalitions that had participated in OOOT outreach. The two primary goals of the RP initiative were to maximize the number of coalitions whose projects were having sustainable impact on their communities (i.e., meaningful projects) and to bring as many coalitions as possible along a trajectory of readiness to conduct similar projects.

Three regional resource centers, each with expertise in one or more areas critical to coalition function, were identified and charged with providing core technical assistance to coalitions in assigned states. Alta Consulting was engaged to develop the National Resource Center on Diversity (NRCD) that would provide information, materials and technical assistance nationally to Last Acts partners and RP coalitions.

One of the most significant conclusions that emerged from the evaluation of these earlier initiatives was the importance of utilizing both national and state-level programs and networks for stimulating and encouraging work in local communities. Projects provided individuals and coalitions with a sense of commitment and belonging to a “broader movement” and an impetus to continue in the face of challenges. For example, individuals and coalitions felt that they could learn from each other via networking and that they could gain momentum from their desire not to let “the movement” down. The sense of community generated optimism that the movement as a whole could make a difference.
These valuable insights were the impetus behind NHPCO’s development of the national consumer-engagement program, Caring Connections, which RWJF funded from 2004 to 2009. Caring Connections provides free resources and information to help people make decisions about end-of-life care and services before a crisis occurs. It designs national campaigns that bring together community, state and national partners working to improve end-of-life care.

At its inception, Caring Connections re-energized coalitions that had developed as part of the Rallying Points initiative. Drawing on the lessons learned by Rallying Points that local and state-level coalitions have few resources and need help focusing on specific activities, Caring Connections improved upon traditional approaches to consumer engagement. It provided coalitions with practical strategies for fundraising and communications, detailed action plans, robust mechanisms to share their work, and opportunities to participate in national initiatives/campaigns.

In designing Caring Connections, NHPCO also took note of the challenges its predecessors faced when engaging consumers in end-of-life issues and set forth to emphasize positive messages in consumer communications about what can be done.

Caring Connections leveraged the power of multiple national voices by providing a small number of simple messages on which to focus. It capitalized on basic advertising principles that suggest that the more times people hear the same message, particularly if it comes through different media and seemingly different sources, the more likely they are to believe it and act on it.

Caring Connections is designed to be a collaborator, striving to “connect” the many organizations that offer consumer information and services with consumers who can benefit from the information. Such organizations include the National Alliance for Hispanic Health and the National Association of Social Workers, among many others. In addition, Caring Connections supports hospices and other community organizations in their outreach efforts at the local level.

In all of its collaborative work, however, the informed, engaged consumer is always at the center of the Caring Connections logic model—a model that was inspired by Liz Kirkman, a hospice volunteer who integrated her commitment to hospice and advance care planning into her daily life (see the sidebar on page 24, “The Engaged Consumer”). Thinking about Liz, Caring Connections focuses on helping consumers:

- Become aware of and connected to one or more elements of the network;
- Get desired information;
- Become prepared to deal with end-of-life experiences;
- Understand and exercise options for care at the end of life;
- Become a resource for friends and family;
- Participate in advocacy for better end-of-life care.

Caring Connections offers an array of consumer engagement programs and activities that build awareness, provide resources, prompt conversations, and improve diversity. A brief overview of Caring Connections activities follows and a detailed list of Caring Connections resources is in the addendum.
LIZ KIRKMAN: THE ENGAGED CONSUMER

Liz Kirkman, a hospice volunteer who worked at The Hospice of the Florida Suncoast (now Suncoast Hospice), was the inspiration behind the Caring Connections model of the “informed, engaged consumer.”

Liz not only volunteered with hospice patients and their families, but she also raised money for the Suncoast program, participated in the speaker’s bureau, trained her dog to be a pet therapist for hospice patients and literally carried a copy of advance directives around her neck as a way of starting conversations with people about the importance of making their wishes known. Liz wasn’t just informed about end-of-life care—she actively worked to ensure that people understood their options and the importance of planning before a crisis.

BUILDING AWARENESS

The “LIVE” Campaign and Its Partners:
The It’s About How You LIVE community engagement campaign, developed in 2005, provides a unified message that compels consumers to take responsibility and action to improve end-of-life care. Hospices, end-of-life coalitions and other health care organizations joined the LIVE Campaign and, by 2008, 770 LIVE partners had received information, resources and/or support and facilitated dialogue in their communities about the need for improved end-of-life care.

Colby Book Tour: In 2006, Caring Connections launched a national book tour in partnership with NHPCO Senior Fellow Bill Colby, the attorney for Nancy Cruzan’s family and author of a Long Goodbye…The Deaths of Nancy Cruzan and Unplugged: Reclaiming Our Right to Die in America. Through this tour, Colby promoted the LIVE campaign and advance care planning in 99 events nationwide—reaching over 15,000 individuals.

“THE CARING CONNECTIONS PROGRAM IS A PERFECT EXAMPLE OF THE ADAGE ‘THINK GLOBALLY, ACT LOCALLY.’ THE GRASSROOTS ENERGY FROM THIS CREATIVE, WELL-EXECUTED INITIATIVE HELPED TO SPARK TENS OF THOUSANDS OF CONVERSATIONS ACROSS THE COUNTRY—THAT, TO ME, IS RESPONSIBILITY IN ACTION.”

BILL COLBY
PROVIDING RESOURCES

Caring Connections Customer Service Center and Helpline:
A comprehensive consumer service center with a toll-free telephone HelpLine began in 2005 to respond to inquiries regarding all aspects of end-of-life care. Many consumers, like Joan in the sidebar below, also call because they are afraid or confused or simply need a compassionate, listening ear.

Caring Connections website:
The Caring Connections website (www.caringinfo.org) provides educational materials and offers consumers and health care professionals contact information for local hospices, as well as information on advance care planning, caregiving, serious illness and grief. More than 54 Caring Connections brochures plus advance directive forms for all 50 states and the District of Columbia can be downloaded from the site free of charge.

PROMPTING ADVANCE CARE PLANNING CONVERSATIONS

- Eleven publications covering various issues surrounding advance care planning are available through Caring Connections—plus bilingual guides in Spanish/English and Mandarin Chinese/English.
- The Advance Care Planning Awareness Ribbon was created, and a promotional campaign was launched on March 31, 2006 in honor of the one-year anniversary of Terri Schiavo’s death. The campaign encourages people to wear a white ribbon to increase awareness about end-of-life discussions and makes available for purchase the It’s About How You LIVE lapel pins and informational lapel-pin cards.
- Caring Connections distributes advance care planning information and advance directive forms—and has provided over 1.3 million free advance directive forms since its inception in 2004.
- In July 2009, Google Health launched a program for users to download and store advance directive documents securely online. Google Health selected Caring Connections as the sole founding partner in this new initiative.


- The first annual National Healthcare Decisions Day took place on April 16, 2008 and has continued each year since. Caring Connections staff provides support for this grassroots effort and hosts the National Healthcare Decisions Day website (www.nationalhealthcaredecisionsday.org).

REDUCING DISPARITIES

Focus Groups:
Caring Connections conducted focus groups in various cities nationwide in 2006-2007 to identify areas of need in underserved populations and determine compelling messaging strategies and resources for consumer groups representing African American, Chinese American, Latino, parents of seriously ill children, parents grieving the loss of a child, and developmentally disabled individuals.
Outreach Guides:
Five outreach guides were developed to help hospices, coalitions and others seeking to expand access to end-of-life care for African Americans, Chinese and Latino populations as well as pediatric patients and those with disabilities.

Bilingual Materials:
Caring Connections developed multiple bilingual and culturally-relevant resources on a variety of end-of-life topics in Spanish/English and Mandarin Chinese/English. It also created bilingual Spanish/English educational materials specifically for parents of seriously ill children or parents of children who are grieving.

Spanish and Multilingual HelpLines:
Caring Connections developed Cuidado con Cariño, a toll-free Spanish HelpLine that offered information and resources for people living with or caring for someone with a serious illness. With strong feedback indicating the need for translations in additional languages, the Spanish HelpLine transitioned to a “Multilingual Line,” with staff responding to calls in over 200 languages.

Pediatric Resources:
In addition to the Pediatric Outreach Guide and multilingual pediatric resources, Caring Connections collaborated to create Partnering for Children, a campaign that focuses on community engagement, creating a virtual resource library, and conducting national media outreach.

REACHING OUT

- In 2008, Caring Connections published the It’s About How You LIVE—In Faith Outreach Guide providing hospices and coalitions with specific ideas and resources to reach out to faith communities. It partnered with the Duke Institute on Care at the End of Life and Project Compassion to create The Unbroken Circle: A Toolkit for Congregations Around Illness, End of Life and Grief.

- Caring Connections developed the It’s About How You LIVE—At Work campaign to help employers support employees who are living with a serious illness, caregiving, or grieving. The cornerstone of the campaign is the It’s About How You LIVE—At Work: An Employer’s Guide to Work-Life Programs and Policies. The initiative also includes consumer brochures related to end-of-life issues in the workplace and a guide to help hospices reach out to local businesses.

SINCE 2004, MORE THAN 1.3 MILLION FREE ADVANCE DIRECTIVES HAVE BEEN DISTRIBUTED BY CARING CONNECTIONS.
CONSUMER ENGAGEMENT AND HEALTH CARE REFORM

In March 2010, Congress passed H.R. 3590, the Patient Protection and Affordable Care Act, which President Obama subsequently signed into law. For more than a year, the end-of-life community was on the edge of its collective seat, watching the political process that consumed health care reform. When the dust settled, hospice advocates celebrated gains such as approval for demonstration projects to test innovative approaches for hospice patients to concurrently receive hospice and other Medicare-covered services, and provisions that allow children enrolled in Medicaid or the Children’s Health Insurance Plan to receive hospice services without foregoing curative treatment related to a terminal illness. NHPCO was in the center of discussions advocating for service delivery approaches that supported the real-life needs of patients and families. It encouraged development of “Advanced Illness Transitional Care Management and Planning” demonstrations projects, which assure that there is a seamless continuum of care and that conversations about transitioning to palliative care are explored throughout the disease trajectory.

The health care debate also revealed that many Americans feel passionate about care at the end of life. This was demonstrated by the media frenzy that resulted from an advance care planning provision in the 2009 House version of the health care reform legislation that would have reimbursed physicians for the time they spent talking with patients about advance care planning. Social networking sites condemned federally created “death panels” and “rationed care,” which quickly spread to major media outlets, the halls of Capitol Hill, and community assembly halls where the nation’s legislators hosted public meetings about health care reform. It’s clear from the furor that erupted over misperceptions of “death panels” with discussions about end-of-life preferences that further education is crucial to improve understanding, acceptance and practice of advance care planning as a process to determine and communicate wishes to receive or withhold life-prolonging treatments.

FURTHER EDUCATION IS CRUCIAL TO IMPROVE UNDERSTANDING, ACCEPTANCE AND PRACTICE OF ADVANCE CARE PLANNING.
A CALL TO ACTION

As the new health care reform law is implemented, it’s abundantly apparent that, as a nation, we must take some important steps if we are to change society’s approach to serious illness, death and dying. Presented here as “needs,” the following are suggested ways that individuals, communities and organizations can assume responsibility for meeting the concerns of those at the end of life:

1. Individuals need to talk about their wishes for care at the end of life with family members, friends and care providers and then document their wishes in writing to better assure that their wishes will be honored;

2. Health care providers need to initiate honest, timely and culturally-relevant discussions about the burdens and benefits of treatment options in the last stages of an illness to assist patients in making informed decisions;

3. Communities need to work together, providing care and support to seriously ill people and their family caregivers to ensure that no one dies alone or in pain;

4. Health care payors need to understand the importance of a continuum of care that would ensure that patients have access to the highest quality care regardless of where they are in the course of an illness. This continuum begins with the introduction of palliative care at the onset of advanced illness while a patient is still pursuing curative treatments to ensure that distressing symptoms and emotional care are addressed promptly, and the ratio of curative and palliative care can be adjusted throughout the illness;

5. Policy makers need to eliminate barriers that prevent timely access to hospice and palliative care;

6. Employers need to support their staff who are living with a serious illness, caring for a loved one or grieving a loss;

7. Researchers need to study end-of-life issues such as the efficacy of life-sustaining and palliative care therapies and the impact of grief on the workplace;

8. The media needs to explore ways to demystify dying and conversations about end-of-life issues in order to normalize the experience for the general public.

No single organization can fully articulate the needs of those living with, or caring for someone, with a serious illness. The needs listed above are an amalgamation of 40-plus years of working with hospices, end-of-life coalitions, funders, policy makers, regulators and individuals working to make the end-of-life experience better for those who face it today, tomorrow and in the years to come.
THE NEED FOR ADDITIONAL SUPPORT

Despite the tremendous work that has been accomplished to change society’s approach to serious illness, death and dying, much more needs to be done – and funding is required to do it. NHPCO has identified specific needs and programs that are worthy of consideration by funders of all types who are interested in continuing to improve end-of-life care in the United States:

1. Individuals need to talk about their wishes for care at the end of life with family members, friends and care providers and then document their wishes in writing.

2. Health care providers need to initiate honest, timely and culturally-relevant discussions about the burdens and benefits of treatment options in the last stages of an illness.

   - Produce and disseminate advance care planning decision tools. Funding is needed to develop decision-making tools that “walk” individuals and families through the advance care planning process, including resuscitation, intubation, health care surrogacy, hospice and other “options” or decision points that comprise the advance care planning process. These tools could be used by physicians and other health providers, faith communities, senior service providers and case managers as well as families.

   - Bring interdisciplinary, palliative care training to medical and social service providers to ensure professionals know how and when to talk about end-of-life care options.

   - Translate end-of-life care informational materials into languages other than English. Caring Connections has developed culturally-relevant and language-specific materials in Spanish and Mandarin Chinese. However, additional funding is needed to meet consumer requests for resources in other languages.
3. Communities need to work together, providing care and support to seriously ill people and their family caregivers to ensure that no one dies alone or in pain.

4. Health care payors need to understand the importance of a continuum of care that would ensure patients have access to the highest quality care regardless of where they are in the course of an illness. This continuum begins with the introduction of palliative care while a patient is still pursuing curative treatments to ensure that distressing symptoms and emotional care are addressed promptly, and the ratio of curative and palliative care can be adjusted throughout the illness.

5. Policy makers need to eliminate barriers that prevent timely access to hospice and palliative care.

6. Employers need to support employees who are living with a serious illness, caring for a loved one or grieving a loss.

- Educate faith, cultural and other community leaders. Consumers often rely on their faith communities and social networks to support them when facing the end of life, death and grief. Funding is needed to disseminate forces and train faith and other leaders to meet the needs of their community members.

- Fund the development of an Advanced Illness Transitional Care Management and Planning demonstration. Demonstration projects would provide people who have serious illness access to palliative care services, end-of-life care planning, counseling, discussions regarding supportive services and care planning delivered by a hospice team prior to eligibility for the Medicare hospice benefit. This information will enable patients and their families to make informed choices from among care options, improve the quality of the care they receive, reduce needless suffering and select the most effective care. It may also encourage patients to elect the Medicare hospice benefit earlier.

- Educate policy experts on the current barriers to accessing palliative and hospice care and potential solutions. End-of-life issues are complex and involve clinical, legal and financial considerations. Policy makers need evidence-based information to guide their thinking. Funding is needed to teach grassroots advocates how to communicate the efficacy of innovative models with policy makers. One such innovative model is the Transitional Care Model (TCM). Under this model, an interdisciplinary team member meets with someone who is hospitalized and his family to coordinate his care. The team member continues to meet with the patient at his home.

- Expand the It's About How You LIVE—At Work Initiative. Funding is needed to expand the It's About How you LIVE—At Work Initiative to help more employers improve their understanding of how to assist employees who are juggling work responsibilities with family caregiving tasks.

- Determine the impact of grief in the workplace. Fund a national study to quantify the costs of grief in relation to employee productivity, health and behavioral health care expenditures and the cost of rehiring employees who quit or are fired because of grief-related issues.
7. Researchers need to study end-of-life issues such as the efficacy of life-sustaining and palliative care therapies and the impact of grief on the workplace.

8. The media need to explore ways to demystify dying and conversations about end-of-life issues in order to normalize the experience for the general public.

- Evaluate TCM and other models of “concurrent care” to determine outcomes, actual costs and cost savings. Funding is needed to support a national research agenda that evaluates access to palliative care, quality of care and cost implications of innovate models of service delivery.

- Repeat national polls on American attitudes about and understanding of end-of-life care issues. Funding is needed to develop and disseminate national data that reflects current perceptions and misperceptions and will help inform the outreach initiatives of stakeholders.

- Gather and implement a national education, outreach, marketing and social media campaign so that all Americans understand how to access quality palliative, chronic and end-of-life care, in accordance with their care needs, in a timely manner. Build upon the success of Caring Connections, National Healthcare Decisions Day and other grassroots, nationally-coordinated efforts to educate the public about advance care planning, hospice, palliative care, grief and pediatric palliative care.

Of all the nationally-focused grant-funded initiatives and special organizations formed since the late 1990s, only a few are still active. The Center to Advance Palliative Care, the EPEC Project (Education on Palliative and End-of-Life Care), End-of-Life Nursing Education Consortium (ELNEC), and Caring Connections are the four significant initiatives that have sustained the core elements of their grant-funded work. Despite the tremendous outcomes achieved by all of these initiatives and organizations, more work must be done to continue the progress of the last 40 years. We need only look to the misinformation and widespread fear of “death panels” that captured our country’s attention during the 2009-2010 health care reform debate as testament to this.

Caring Connections is seeking partners to help accomplish these targeted goals. Rigorous approaches to public awareness of and engagement in issues related to end-of-life care are essential if American society is to advance beyond the heartbreaking encounters with the medical and legal arenas experienced by the Quinlan, Cruzan and Schiavo families …and by families today who privately endure the sadness that results when the wishes of those who are dying go unknown or unacknowledged. Public awareness and engagement are vital steps toward the greater goal of creating a world where individuals and families facing serious illness, death and grief will experience the best that human-kind can offer.
Caring Connections Resources

The resources under each topic can be found on the Caring Connections website – www.CaringInfo.org. Most are listed under resources or brochures and the rest are under the Community section.

Caring Connections
Advance care planning, caregiving, serious illness, grief, community outreach and workplace

- www.caringinfo.org
- caringinfo@nhpc.org
- HelpLine: 800-658-8898
- Multilingual Line: 877.658.8896

Advance Directives/Advance Care Planning

- Artificial Nutrition and Hydration at the End of Life
- Communicating End-of-Life Wishes
- Conversations Before the Crisis
- End-of-Life Decisions
- If You or Someone You Love is Very Ill...Ask Tough Questions
- Leaving a Legacy
- Saying Goodbye
- Understanding Advance Directives

Websites
- National Healthcare Decisions Day: www.nationalhealthcaredecisionsday.org
- The Physicians Orders for Life-Sustaining Treatment Paradigm: www.polst.org

Caringgiving

- End-of-Life Caregiving Booklet
- How to Support Someone Caring for Another

Websites
- Family Caregiver Alliance: www.caregiver.org

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Caringgiving

- End-of-Life Caregiving Booklet
- How to Support Someone Caring for Another

Websites
- Family Caregiver Alliance: www.caregiver.org

Grief

- Supporting Someone Who is Grieving
- There is no Wrong or Right Way to Grieve After a Loss

Pain

- How to Manage Your Pain
- Using Narcotics Safely

Pediatric

- Helping Children Cope with the Loss of a Loved One
- Talking to Your Child’s Doctor: When Your Child Has a Serious Illness
- Talking With Your Child About His or Her Illness
- When a Child Dies: A Guide for Family and Friends
- When Your Child is in Pain

Websites
- Children’s Hospice and Palliative Care Coalition: www.childrenshospice.org
- Partnering for Children: www.partneringforchildren.org
- Partnership for Parents: www.partnershipforparents.org

Professional Resources

- A Guide for Clinicians
- Advice for Physicians Caring for Dying Patients
- Hospice Patient Rights
- Palliative Care: Information and Resources for Healthcare Professionals

Websites
- Center to Advance Palliative Care: www.capc.org
• Hospice and Palliative Nurses Association: www.hpna.org

SERIOUS ILLNESS
• Living with Serious Illness
• When Someone you Care About is Seriously Ill

SPIRITUALITY
• Offering Spiritual Support for Family or Friends

SPANISH/ENGLISH BILINGUAL RESOURCES
• Afliccion por una perdida—Grief and Loss in Spanish/English
• Apoyo para el cuidador—How to Support Someone Caring for Another in Spanish/English
• Cuidado Paliativo o Cuidoado de Hospice—Hospice and Palliative Care in Spanish/English
• Las etapas en los finales de la vida - Phases at the End of Life in Spanish/English
• Mis deseos a la atencion de mi Salud: Medicas o Directivas Anticipadas—Advance Directives: My Wishes for Medical Attention in Spanish/English

PEDiatric SPANISH/ENGLISH BILINGUAL RESOURCES
• Como Ayudar a los Ninos a Afrontar la Muerte de un ser Querido—Helping Children Cope with the Death of a Loved One in Spanish/English
• Cuando Su Hijo Tiene Dolor—When Your Child is in Pain in Spanish/English
• Hablando Con Su Hijo Sobre Su Enfermedad—Talking With Your Child About His or Her Illness in Spanish/English
• Hablando Con el Medico Sobre Su Hijo: Cuando Su Nino—Talking to Your Child’s Doctor: When Your Child Has a Serious Illness in Spanish/English

Websites
• Padres con Padres: www.padresconpadres.com

MANDARIN CHINESE/ENGLISH BILINGUAL RESOURCES
• Hospice Care
• Palliative Care
• There is No Wrong or Right Way to Grieve After a Loss
• Understanding Advance Directives
• Understanding the Dying Process

Websites
• Chinese American Coalition for Compassionate Care: www.caccc-usa.org

WORKPLACE
• A Guide for Working Caregivers
• Helping Employees Cope After a Critical Incident
• It’s About How You LIVE—at Work: An Employer’s Guide to Work-Life Programs and Policies
• Supporting Someone Who is Grieving
• When a Co-Worker Dies
• When an Employee Dies
• When an Employee is Seriously Ill
• When an Employee Suffers a Loss
This timeline touches on factors in the last 40-plus years that have influenced public perception about end-of-life care, including several key elements, events and programs that will be explored in-depth in subsequent pages.

1967: Dame Cicely Saunders founds the first modern hospice—St. Christopher’s Hospice—outside of London.

1969: Dr. Elisabeth Kübler-Ross publishes On Death and Dying.

1972: Kübler-Ross testifies at the first national death-with-dignity hearings, entitled “Death With Dignity: An Inquiry into Related Public Issues”, which are conducted by the U.S. Senate Special Committee on Aging.


1974: The first hospice legislation is introduced to provide federal funds for hospice programs. However, the legislation is not enacted.

1975: Karen Ann Quinlan, age 21, falls into a coma following a drug overdose and is placed on artificial life support, including a respirator and a nasogastric tube for artificial nutrition and hydration.

1976: The New Jersey Supreme Court rules that Quinlan has a constitutional right to privacy that her father can exercise on her behalf. Her father exercises this right by having her slowly weaned from the respirator. She lives in a persistent vegetative state for another ten years.

1976: California becomes the first state to enact legislation allowing individuals to complete advance directives that outline care they do and do not want to receive should they become unable to make or communicate their health care decisions.

1978: A U.S. Department of Health, Education and Welfare task force reports that hospice is a valuable delivery system, worthy of federal support.

1979: The Health Care Financing Administration (now The Centers for Medicare and Medicaid Services or CMS) initiates demonstration programs at 26 hospices to assess the cost effectiveness of hospice care and to help determine the essential characteristics of a hospice organization, including the services to be provided.

1980: The W.K. Kellogg Foundation awards a grant to the Joint Commission on Accreditation of Hospitals (now the Joint Commission) to develop standards for hospice accreditation.

1981: Hospices begin caring for patients who have a new disease called Gay Related Immune Deficiency, later renamed the Acquired Immune Deficiency Syndrome (AIDS).


1983: Nancy Cruzan, age 25, has a feeding tube surgically implanted to provide long-term care for her following a car accident that leaves her in a permanent vegetative state.

1984: The Joint Commission initiates hospice accreditation.

1986: Congress makes permanent the Medicare Hospice Benefit, giving states the option of including hospice in their Medicaid programs. Hospice care also becomes available to terminally ill nursing home residents.

1988: The Missouri Supreme Court rules that Cruzan’s feeding tube cannot be removed without clear instruction or convincing evidence that she did not want a feeding tube.

1989: The U.S. Supreme Court agrees to hear the Cruzan case.

1990: Terri Schiavo, age 27, experiences respiratory and cardiac arrest leading to a persistent vegetative state and is hospitalized with a feeding tube inserted.

1990: In a 5-4 decision, the Supreme Court rules against the Cruzan family, stating that the Missouri ruling did not violate the federal constitution, and, “unless Nancy Cruzan had left clear and convincing evidence of her wish to remove the feeding tube, it had to stay in place.”

1991: Following testimony from two witnesses that Cruzan had expressed wishes not to be kept alive artificially, her feeding tube is removed, and she dies 11 days later.

1991: The Patient Self Determination Act is enacted, requiring health care institutions to provide education and information about advance care directives.


1993: Schiavo’s husband and parents initiate legal battles to determine who can make her medical decisions and ultimately whether artificial nutrition and hydration can be stopped.

1995: The Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) Hospice Benefit is implemented on June 1, 1995. It mirrors the Medicare Hospice Benefit in conditions of participation and reimbursement.

1995: A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) is published—showing the barriers to patient/physician communication about end-of-life care exist in even the best hospitals.


1996: Major grant makers, including the RWJF and Soros Foundation, invest significantly in research, program initiatives, public forums and conferences to transform the culture of dying and improve care at the end of life.

1996: RWJF funds Promoting Excellence in End-of-life Care to identify, promote and institutionalize care practices that allow seriously ill people and their families to experience physical, psychological, spiritual and emotional comfort at the end of life.

1997: The American Medical Association begins development and dissemination of the RWJF-funded Education on Palliative and End-of-Life Care (EPEC) core curriculum.

1997: Congress passes legislation barring taxpayer dollars from financing physician-assisted suicide. The U.S. Supreme Court rules that mentally competent terminally ill people do not have a constitutional right to physician-assisted suicide, leaving the issue up to the states. Oregon voters affirm the right to physician-assisted suicide by passing for the second time its “Death with Dignity Act.”

1997: RWJF funds the Community-State Partnerships to Improve End-of-life Care.


1998: The Annenberg Center for Health Sciences and the National Hospice Foundation releases Care Beyond Care: Physician Education in End-of-Life Care.

1998: A consumer advocacy group, Choice in Dying, is renamed Partnership for Caring: America's Voices for the Dying and becomes the program office for Last Acts, a program of RWJF.

1998: The Duke Institute on Care at the End of Life is established.

1999: RWJF funds the Center to Advance Palliative Care (CAPC) at the Mount Sinai School of Medicine.

2000: The PBS series On Our Own Terms: Moyers on Dying in America is the focus of national education and engagement programs, generating record viewership for a PBS series.

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2000: The End-of-Life Nursing Education Consortium (ELNEC) project, a national education initiative to improve palliative care.

2001: The Children's Project on Palliative/Hospice Services releases A Call for Change: Recommendations to Improve the Care of Children Living with Life-Threatening Conditions.

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2002: The Department of Veterans Affairs launches a program to increase veterans' access to hospice and palliative services while providing educational opportunities for clinicians in veterans' health care facilities.

2002: RWJF's Last Acts campaign launches Rallying Points, an initiative to support local community efforts to improve care and caring near the end of life.

2002: A Federal court upholds Oregon's law that permits physician-assisted suicide.


2004: Hospice reaches the million-person mark, with more than one million Americans receiving hospice care.

2004: The National Consensus Project, a consortium of palliative care and hospice organizations, publishes the Clinical Practice Guidelines for Quality Palliative Care.

2004: NHPCO creates the consumer-engagement initiative, Caring Connections, after receiving a RWJF grant to advance public understanding and awareness of end-of-life care.

2005: NHPCO's Caring Connections launches the comprehensive, national campaign, "It's About How You LIVE."

2005: Schiavo's parents lose their long and very public legal battle to keep Schiavo alive artificially, and her husband directs hospice staff to cease artificial nutrition and hydration. Schiavo dies 13 days later.

2005: The Department of Veterans Affairs releases the report, VA Transforms End-of-Life Care for Veterans.


2008: The inaugural National Healthcare Decisions Day is held on April 16.

2009: NHPCO announces that a record number of volunteers—estimated at 550,000—contributed their time in service to hospice patients in 2008.

2009: NHPCO publishes The Standards of Practice for Pediatric Palliative Care and Hospice, along with the companion publication Facts and Figures on Pediatric Palliative and Hospice Care in America.

2009: NHPCO's Caring Connections and Google Health partner to allow people to access advance directives online.
