

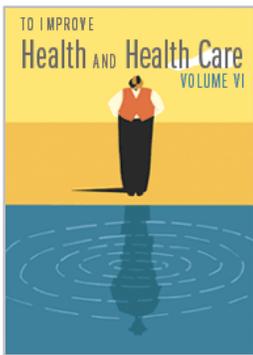
The Foundation's *End-of-Life* Programs: Changing the American Way of Death

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Robert Wood Johnson Foundation

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Editor's Introduction

Since 1996, the Foundation has invested more than \$148 million to improve care at the end of life. This chapter, by Ethan Bronner, an editor at the *New York Times*, takes a comprehensive look at this area of grantmaking, explaining the reason the Foundation entered the field, the logic behind its strategy, and the outcomes that have emerged so far. It illustrates how a foundation can become involved in a burgeoning social movement and help give it vitality and direction.

During the 1980s and the early 1990s, Americans began to be concerned about the long period of suffering many people endured before they died. States passed laws allowing people to sign a living will, durable power of attorney, or health care proxy. Courts wrestled with issues of whether to authorize treatments that would prolong life but not restore its quality. The hospice movement became widely recognized, and hospice services were covered by Medicare. At the same time, prestigious physicians discussed, in the pages of respected medical journals, the idea that physicians should be allowed to help terminally ill patients die; Dr. Jack Kevorkian was helping people who wanted to die do so; and the Hemlock Society's book, *Final Exit*, which told readers how to commit suicide, became a best seller.

In 1988, the Foundation funded a large multi-year research study of alternate approaches to improving care at the end of life. The study found that, even with the new approaches, people still died in uncontrolled pain, hooked up to machines until just a few hours before they died; that few patients had advance directives such as a living will; and that even if they did, the directives weren't followed.⁸ The results of this study led to the Robert Wood Johnson Foundation's major involvement in improving care at the end of life. (The Soros Foundation, too, has worked to improve the current culture of dying through its project on Death in America.)

At its heart, this chapter is a case study of the strategy involved in building a field by supporting thinkers, doers, and communicators who devote their professional attention to this important work. The Foundation's grantmaking in this field is generally regarded as an example of "strategic philanthropy." A small team of Foundation staff members selected three areas in which they felt the Foundation could make a difference: improving the education of practitioners; building model palliative care programs at hospitals; and raising awareness among the public. Although it is difficult to assess the success and failure of field-building efforts, the evidence presented by Bronner makes a

strong case for initial success.

Perhaps what makes this area so compelling is the tension between the human and the technical. Most people who watch loved ones die after a long illness come away as advocates for improving care at the end of life and placing more emphasis on pain management. Yet this is a world with continuously emerging medical technology that can solve an increasing number of physical problems. The decision of when to switch from an all-out effort to cure a person to an effort to relieve suffering so that death can occur with comfort and dignity remains a wrenching one.

Notes

*Lynn, J. "Unexpected Returns: Insights from Support." In *To Improve Health and Health Care 1997: The Robert Wood Johnson Foundation Anthology*. San Francisco: Jossey-Bass, 1997.

Diane Meier, a geriatrician at the Mount Sinai School of Medicine in New York City, was no stranger to suffering when, in 1994, she came upon something that shocked her: a seventy-three-year-old terminal cancer patient who had been strapped to his bed and force-fed for a month. Before his lung tumor metastasized to the brain and grew so large that it prevented him from speaking, the patient had repeatedly requested that no extraordinary measures be used to keep him alive. Two years earlier, he had watched his wife die of lung cancer, and under no circumstances did he wish to repeat her experience with diagnostic tests and life-prolonging treatment. He wanted to return home and die in peace.

Some months earlier, the patient had been permitted to go home, but after three grand mal seizures he was brought to the emergency room and put under the care of a new group of physicians, who pursued aggressive intervention. After he repeatedly grabbed at his feeding tube and removed it, his wrists were restrained and the tube was placed beyond his reach. That was when Diane Meier saw him. When she asked the resident on duty why the patient was being treated this way, the answer was, "Otherwise he will die." Shortly thereafter, on the twenty-ninth day of such treatment, the man's lungs and heart stopped, and he did die.

To Meier, everything about the way the man's life ended was not only tragic for him personally but also indicative of the failure of American medicine to view death in its proper context. As she and two fellow physicians at Mount Sinai, R. Sean Morrison and Christine Cassel, wrote in an article on the case in the *New England Journal of Medicine* in 1996, "The experience with this patient is a disturbing illustration of

the care received by many terminally ill patients in U.S. hospitals... . Once an informed decision has been made to forgo life-prolonging therapy, the goal of care should be palliation... . It is time to ask ourselves what more can be done to relieve the suffering of patients who are dying. We need to identify the barriers to good palliative care, and address them rapidly so that this patient's experience becomes rare."¹

In palliative care, control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is considered to be the best quality of life for patients and their families. This definition more closely fits the better-known and somewhat narrower concept of hospice care. The umbrella of palliative care includes hospice, which provides care for people recognized to be terminally ill and where comfort and quality of life are the only goals. But palliative care also can pursue comfort and treatment simultaneously, as in the case of patients undergoing curative treatment. (To qualify for Medicare reimbursement, hospice care requires a prognosis of death within six months; palliative care operates under no specific time frame.)

To some people, the idea of death, peaceful or otherwise, as a goal of medicine seems counterintuitive and unsettling. Medical success over the past century has been defined precisely by the myriad ways that death has been staved off. Indeed, as medical ethicist Daniel Callahan has pointed out, each technological advance that prolongs life quickly becomes routine and mandatory.² Yet Meier said that as she began to focus on the problem, she realized that prolonging life brings with it a new set of profound dilemmas.

"All life ends in death," Meier said one morning as she sat in her modest, packed office on the tenth floor of the Hertzberg Palliative Care Institute at Mount Sinai Hospital. "There has been an unexamined belief that with enough research, all causes of death will be defeated and we will live forever. Is this desirable? Is it good? We should also be focusing on aging gracefully. There has developed a kind of false choice: care based on maximum prolongation of life versus care based on comfort."

Meier is the director of both the Hertzberg Institute and the Center to Advance Palliative Care, which is also at Mount Sinai and funded by the Robert Wood Johnson Foundation. Meier makes another point about end-of-life care: "All surveys show that no one wants to die tethered to machinery. People want their pain controlled, they want to strengthen their relationships with family and loved ones, they want to reduce the burden on their families, and they want to complete tasks. We may steal these opportunities with

technology.”

THE FOUNDATION’S APPROACH TO END-OF-LIFE PROGRAMS

The Foundation’s interest in this area began in 1989 when it funded a five-year study of death in hospitals. Called SUPPORT, for Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, the \$28 million study looked at nearly ten thousand critically ill patients in five major medical centers in the United States. The resulting report, published in 1995 and given wide publicity in the media, made it clear that most Americans die in hospitals, often alone and in pain, after days or weeks of futile treatment, with little advance planning, and at high cost to the institution and the family. Some patients had specified through a living will that they did not want such intervention, and many died attached to a machine in an intensive care unit. *Newsweek* summed up the findings of SUPPORT this way: “The larger problem, most analysts agree, is that American medicine lacks any concept of death as a part of life.”

Commenting on SUPPORT in 1997, one of the co-investigators, Dr. Joanne Lynn, wrote, “Surely we can do better. Pain could be much more of a focus. Decisions could be made in advance, and care plans shaped much more creatively. Clearly, long-standing habits exist for a myriad of poorly understood reasons and do not yield readily to change. It may well be that change requires a much more fundamental restructuring of service supply, incentives, and rewards.”³

Motivated by the distressing findings of SUPPORT, the Foundation, too, concluded that a major, wide-ranging effort was needed to bring attention to the importance of improving the quality of care toward the end of people’s lives. It adopted a three-pronged strategy:

- *Professional education*: changing the curriculum in medical and nursing schools, modifying courses and textbooks to include end-of-life care, adding palliative care to licensure and certification examinations, training medical and nursing school faculty and practitioners, and supporting articles for professional journals such as the *Journal of the American Medical Association* and the *American Journal of Nursing*.
- *Institutional change*: building palliative care capacity in the nation’s hospitals, where more than half of Americans die; working with hospital accreditation agencies to develop pain management standards; and stimulating innovative programs that provide palliative care.
- *Public engagement*: creating a new vision of end-of-life care through the media (both information and entertainment), and getting individuals and communities to take action to improve care for dying people and their families.

The strategy has a logical flow. “We’re trying to change the attitude of the medical and nursing

community,” says Rosemary Gibson, a senior program officer at the Foundation who chairs its end-of-life team. “Without their support, little will happen. But it’s not enough. We’ve got to institutionalize palliative care by making it a normal part of medical and nursing care of seriously ill patients and by creating centers of excellence. And we’ve got to go farther; we’ve got to change the culture of American society. What we’re really trying to do is make this mainstream—to make it part of the nation’s genetic code.”

It seems paradoxical that as technology prolongs life, a movement should take root that focuses on accepting death and improving the care given to dying people. Researchers say that interest in palliative care has arisen now because of several intersecting factors. The first is demographic. People in the baby boom generation—the postwar population bulge—have come face-to-face in recent years with the lackluster care given their parents as they age and die. The second reason for the new attention is the focus on physician-assisted suicide that has been created by Dr. Jack Kevorkian in the late 1980s and the 1990s, by an Oregon law permitting it, and by a U.S. Supreme Court decision adjudicating it. Third was the unequivocal nature of SUPPORT’s findings, confirming everyone’s worst fears about the kind of care Americans receive. Finally, advocates say, a number of doctors and nurses in their forties and fifties who were becoming disillusioned with their profession because of managed care’s growing emphasis on the bottom line found in palliative care a source of renewed inspiration. Together, these factors have created the seeds of change. But shifting something as fundamental as how Americans die will not be simple or quick. According to Vicki Weisfeld, a Robert Wood Johnson Foundation senior communications officer and member of the Foundation’s end-of-life team:

Our biggest enemy is the status quo. Nobody wants to torture dying people, yet everyone has had these experiences. They come away thinking, ‘I don’t want anyone else to go through what my mother went through,’ or ‘If only everyone could have as peaceful a passing as Aunt Tilly.’ But everyone interprets the experience as a totally idiosyncratic confluence of disease, personality, doctor, and so on. They don’t see it as reflecting systemic issues. But it is. We are trying to be catalysts, to get people to start paying attention, to create the conditions so that in ten to fifteen years end-of-life care will be seen not as a separate entity but as a logical extension of chronic care.

CHANGING THE ATTITUDES OF HEALTH PROFESSIONALS

Changing a system requires, as much as anything, changing the views and practices of its leaders and practitioners—in this case, the members of the medical and nursing professions. The Robert Wood Johnson Foundation has focused part of its funding of end-of-life care on modifying how doctors and nurses are trained. This is vital because, as George Annas, a Boston University law professor and medical

ethicist, has argued, “Physicians simply have never taken the rights of hospitalized patients seriously. The central reason is that in the modern teaching hospital, patient care is often a distant third goal after teaching and research. In the high-tech, high-pressure environment, there is little room for thoughtfulness, for the intrusion of human values, or for conversation with the patient or family.”⁴

In 1998, the Foundation gave \$832,000 to Stanford University and \$998,000 to Massachusetts General Hospital to provide in-depth training to medical school faculty so they are equipped to teach end-of-life care to their students and other faculty members. Stanford trains medical faculty members from across the country in a month-long program, and the people it trains then act as resources for faculty members and others in their home institution. The grant to Massachusetts General Hospital helped jump start the Center for Palliative Care at the Harvard Medical School, which trains physicians and nurse educators to become expert—and to train others—in the clinical practice and teaching of comprehensive, interdisciplinary palliative care.

With funding from the Robert Wood Johnson Foundation, Tom Bowles, president of the National Board of Medical Examiners, took on the task of increasing the quantity and quality of end-of-life questions on the U.S. Medical Licensing Examination. David Weissman, professor of internal medicine at the Medical College of Wisconsin, has been working to overcome the core barriers to training regarding end-of-life care in the residency setting. Among the projects carried out under his Robert Wood Johnson Foundation grant was a one-year pilot program for thirty residency programs in the Midwest; it has subsequently attracted nearly two hundred residency programs. The Foundation has also funded a program to train practicing physicians, called Education for Physicians on End-of-Life Care. The training sessions have consistently been oversubscribed, and the training materials are in great demand.

The Foundation also gave out grants to assess how medical textbooks treat end-of-life care. Stephen McPhee, a physician at the University of California, San Francisco, School of Medicine and director of the medical textbook project, said that leading medical textbooks were markedly deficient in end-of-life issues. Chapters on fatal diseases focus on prognosis and are rarely concerned with treating symptoms, decision making about terminal care, and the impact of death on a patient’s family.

McPhee and his colleagues carried out a study of medical textbooks. They set up categories of topics that should be covered, among them epidemiology, natural history, pain management, psychological issues such as depression and fear, and social and demographic issues as well as cultural and spiritual ones. The

results were published in the *Journal of the American Medical Association*.⁵ The investigators reported that, overall, helpful information was found in about 24 percent of those categories. In more than 56 percent of them, discussion of relevant end-of-life topics was entirely absent.

More than a year later, McPhee and his colleagues reported on follow-up they carried out with editors and publishers.⁶ They found that of the fifty leading medical textbooks, more than one-third were planning to expand or had already expanded end-of-life care content in their next edition. They also received six personal letters from editors and publishers supportive of the project, including a poignant one from a textbook editor who was himself dying of cancer at the time he wrote. Meanwhile, as McPhee pointed out in his follow-up, much work remains to be done. Most best-selling textbooks, including oncology (cancer) and hematology (blood diseases) texts, have not responded to the suggestions of their specialty board and others to improve clinical education in end-of-life care.

Of course, training doctors only goes so far. Nurses actually provide most of the care to the dying, and in nursing homes, where a growing proportion of people die, nurses provide almost all of the professional services. So the Foundation is funding a high-quality palliative care training program for nurses, attempting to increase the attention given to palliative care in the nursing school curriculum, analyzing and trying to improve how nursing textbooks treat end-of-life issues,⁷ and working to have end-of-life care made a part of the nurse licensing exams.

BRINGING PALLIATIVE CARE INTO THE MEDICAL MAINSTREAM
To institutionalize palliative care and make it a normal part of the care of gravely ill patients, the Foundation has worked to create a more hospitable environment for it in the nation's health care facilities. It has given out a range of grants to bring about institutional change. Two of the more compelling are an award to Mount Sinai Medical Center in New York City to establish the Center to Advance Palliative Care, which focuses on integrating palliative care into hospitals, and an award to the Practical Ethics Center of the University of Montana, Missoula, for a program called Promoting Excellence in End-of-Life Care, with the goal of encouraging innovative demonstration projects to improve care for dying patients.

Mount Sinai's Palliative Care Unit

A meeting of the palliative care unit at Mount Sinai at 8:00 A.M. on a November morning illustrates one of the approaches supported by the Foundation. Seven specialists—a social worker, a nurse practitioner, two nurses, and three doctors—gather in the office of Jane Morris, a nurse who is the unit's clinical

coordinator, for the weekly meeting. They examine a list of ten very ill patients, most of whom are elderly. There is also a thirty-two-year-old male with a failed intestinal transplant and a forty-year-old male with hepatitis C. Coffee cups sit alongside clipboards; the high pitch of beepers frequently interrupts the discussion. A sense of camaraderie and shared mission pervades the room.

“Miss K. is a seventy-four-year-old with hypertension and dementia,” Tim McGrath, the nurse practitioner, tells his colleagues. “She has three sons and all are on their way here because she recently attempted suicide.”

“What about her pain?” asks Diane Meier, the group’s leader. “Does she have pressure sores? She’s a very large woman who has been in bed a very long time.”

In this as in other cases, drug doses and therapies are discussed and debated. Often the question comes up: Has she made her wishes known?

After the meeting, McGrath goes to the gastrointestinal care center to check on a number of patients. He focuses on their comfort and personal and human needs rather than on the progress of their medical therapies. His first stop is Don Koll, a seventy-eight-year-old retired actor who has carcinoid syndrome, meaning that he suffers from a web of related symptoms, such as cramps and diarrhea, caused by tumors in his digestive track. A once-strapping 5'10" and 190 pounds, Koll is down to 140. Having earned a good living from advertisements of, among other things, Swift Butterball turkeys (he was the handsome, kindly looking father who told his wife that the turkey was “really juicy”), Koll today can’t keep his food down. It is a cruel paradox, of which Koll is aware. McGrath asks about his walking.

“I still can only go so far and then I have to sit and pant,” comes the matter-of-fact reply. They also discuss where Koll should go when leaving the hospital.

After McGrath moves on to other patients, Koll speaks of the value of his visit: “I’m prone to depression, so it helps me when they come around to talk like this,” he said. “The rest of the staff here on the ward are really too busy to do it, so it is good to have these palliative care folks come. I’ll be leaving here in a few days, and they are helping me make those arrangements.”

Some minutes later, McGrath is on the telephone at the nurses’ station talking with a member of a

Hispanic family in the Bronx that wants to bring back their mother, who has liver cancer.

“What do they hope to accomplish by bringing her into the hospital?” McGrath asks, speaking to a family member whose English is fluent. “The IV fluid is not going to change things. Our goal is to keep her at home and comfortable as long as possible.”

The children decide to bring their mother in anyway, in the faint hope that her condition will improve in the hospital.

Promoting Excellence in End-of-Life Care

In 1997, the \$12-million Promoting Excellence in End-of-Life Care program, based at the University of Montana, Missoula, issued a call for creative strategies for delivering palliative care in difficult clinical contexts. Some 678 letters of intent arrived from fifty states and two territories. After an intense review process, twenty-two projects were chosen, each funded for up to \$450,000 over three years. The three broad priority areas were (1) special populations, including children, Native Americans, the seriously mentally ill, and urban African Americans; (2) specific diseases and conditions, including Alzheimer’s and advanced HIV; and (3) challenging clinical settings, such as nursing homes, cancer centers, rural communities, and maximum-security prisons. The aim of the projects is to build models that can be sustained and adopted more widely. Jeanne Twohig, the deputy director of Promoting Excellence, says that in many of those projects that aim is being realized.

Among the special populations receiving support are Alaskan Natives served by the Bristol Bay Area Health Corporation. The project has been dubbed *Ikayurtem Unatai*, which in Yup’ik means Helping Hands; it aims at providing end-of-life care to thirty-two villages throughout a Bristol Bay area of forty-seven thousand square-miles. Village leaders say they have been unhappy that terminally ill elders are often flown to a hospital hundreds of miles away in Dillingham or Anchorage, where they spend the last days of their lives and die far from village and family.

“They knew that when an elder was sick they would probably never see the person again, and that caused a lot of trauma,” said Christine DeCourtney, who helped establish and run the program for three years and who remains a consultant in Dillingham. “The program has proved very popular. The families are now more involved in care. It used to be that 33 percent were dying in the villages. Now it is 77 percent.” Twohig added:

When someone is about to die, they have what amounts to a town meeting to provide volunteers so the person can die at home. They have produced a brochure in Yup'ik for volunteers, which talks about issues specific to their culture such as helping families dry their berries and hang their fish. Now that patients are staying at home, there is a huge cost saving, because they are not airlifting them, and there is real improvement in grief and bereavement. And the project is being picked up by the Alaskan Native Tribal Health Consortium in Anchorage to spread it across the twelve different native regions.

In essence, DeCourtney explained, the program returns death to the place it had for centuries in Yup'ik culture, but with the addition of Western medicine to reduce pain and of case managers and social workers to reduce anxiety.

Although about 85 percent of whites generally say they wish to die at home, the numbers are different for Latinos and African Americans. About a third of both Latinos and blacks say they do not want to die at home, according to Dr. Jerome Kurent, an associate professor of medicine at the Medical University of South Carolina, another grant recipient. Among the reasons given for preferring to die in a hospital, he said, were that better care and equipment were available there and that some members of the community are not comfortable continuing to live in a house where someone has died.

Much about the difference in group attitude toward pain and dying is unexplored, but there is a body of research that speaks of broad differences among groups. “We’ve come very far in defining what a good death means for most white, middle-class Americans,” says Dr. Leslie Blackhall of the University of Virginia’s Center for Biomedical Ethics. “But we have to be careful that we don’t project those ideas on people from different cultural backgrounds who may want more lifesaving technology than we would want, who may not want to make all the decisions.”⁸

There is also research indicating that those in racial and ethnic minorities in the United States lack access to treatment for pain, and that this may contribute to their desire to go to the hospital when very ill. Contributing factors include physicians’ reluctance to prescribe (and patients’ reluctance to use) powerful medication, fear of addiction, and the high cost of drugs. In addition, preliminary evidence indicates that pharmacies in neighborhoods where most residents are not white are less likely to carry opioids than pharmacies in predominantly white neighborhoods.⁹

To promote greater education in end-of-life issues in South Carolina, Kurent and his team engaged

ministers in the community, who went through some twenty hours of workshops on care options and issues of spirituality, taboo, and myth. Among the issues discussed was pain management. Kurent said some elderly members of the community considered pain upon dying to be God's wish, or even punishment, and that sensitive discussion of pain among the dying was, therefore, essential.

In Birmingham, Alabama, the Balm of Gilead, another grant recipient, seeks to integrate existing acute care and end-of-life care throughout Jefferson County and to identify patients who need help earlier. It focuses on medically underserved people with terminal illnesses who have no place to live or need support services at home.

Balm of Gilead provides palliative care at a dedicated ten-bed unit on the fourth floor of Cooper Green Hospital. Each room is furnished and decorated in homelike fashion by a local church or community group. Throughout the hospital, Balm of Gilead promotes the idea of addressing pain as a fifth vital sign and has introduced advance directives into the hospital and its clinics so that patients' wishes are known prior to admission. Since such directives were not widely used by the patients served by the hospital, the staff developed an interview script for use when speaking with patients and families. This has resulted in a much higher rate of acceptance of those documents, says Balm of Gilead's director, F. Amos Bailey. According to the Robert Wood Johnson Foundation's Rosemary Gibson, the project has stimulated five other hospitals in Birmingham, among them the University of Alabama at Birmingham, to establish palliative care programs.

CHANGING PUBLIC ATTITUDES

Public education is central to changing Americans' expectations about the kind of care seriously ill patients should receive, and the Foundation has invested in a variety of initiatives aimed at increasing knowledge and shifting popular attitudes.

Last Acts® is a campaign of more than nine hundred partner organizations working to change the public's attitude toward end-of-life care. Former first lady Rosalynn Carter serves as its honorary chairwoman. Last Acts holds national and regional conferences about end-of-life care, works with policy makers and the media, publishes a quarterly newsletter, and has established a Web site (www.lastacts.org). Among Last Acts' publications are definitions of palliative care (endorsed by more than 150 groups), a series of policy briefs, and a sheet with suggestions of what to do if you or someone you love is very ill. It offers guidelines for questions to ask of the doctor ("If I reach a point where I am too sick to speak for

myself, how will you make decisions about my care?”), the family (“Will you respect my wants and needs, even if they’re different from what they used to be, or if you think they are strange or silly?”), and the clergy (“If I have negative feelings like frustration, sadness, despair, anger at God or life, will you listen empathetically?”).

Last Acts includes a Writers Project, based in Los Angeles. Run by Bill Duke, a former newspaperman and longtime public relations professional, the project has, since 1998, made end-of-life experts and plot lines available to script writers and producers of television dramas. Several of its story ideas have appeared within episodes of the highly popular NBC series “ER” and others in programs such as “Gideon’s Crossing,” “NYPD Blue,” and “City of Angels.” In two late-2000 episodes of “ER,” the death of Dr. Green’s father explored the emotional as well as the medical needs of the dying.

Duke also worked with HBO on the Mike Nichols version (filmed in Great Britain) of the Pulitzer Prize-winning Broadway play “Wit,” starring Emma Thompson, about a sharp-tongued professor dying of ovarian cancer. Last Acts made a technical expert available on the set to be sure the show accurately depicted hospital care around 1990.

“Some people ask how we evaluate our effectiveness,” Duke said, “and that is a fair question. We are not dealing here with something as straightforward as product placement. We are dealing with ideas. But I can tell you this: until this year, I hadn’t ever heard phrases such as ‘palliative care’ used on television.” Duke added, “By watching these shows, people may have received their first exposure to how terminal illness is treated today and what they can do to make their final days more comfortable—more emotionally satisfying.”

The Foundation’s single biggest investment in public education, some \$2.75 million, was in cosponsoring a widely viewed and critically acclaimed, four-part, six-hour PBS documentary with Bill Moyers on dying in America, called “On Our Own Terms.” Julie Salomon, the television critic of the *New York Times*, called it “an extraordinary guide” and “panoramic and often profoundly moving.”

Shown across the country in September 2000 and viewed by twenty million people, the series opened with Moyers speaking directly to the viewers:

Like you, I don’t want to think about death, especially my own. But I’ve realized that death is

pushing through the door we try to keep so firmly shut. Parents age before our eyes. AIDS and cancer take friends and loved ones. And baby boomers, that most powerful generation in our culture, face their own mortality even as they care for their aging parents. So, like it or not, we can't push death back through the door. That's one reason we did this series. The other is that there is a movement afoot driven by our hope for a better death.

The series took the viewers on what it called "intimate journeys of the dying." The first episode, called "Living with Dying," focused on Bill Bartholome, a Kansas City pediatrician in his fifties with three daughters, who has terminal cancer of the esophagus. He decides to stay away from chemotherapy and other aggressive anticancer treatments and keeps a journal on the months and years that end in his death. Bartholome tells Moyers that living in the light of dying offers an entirely new perspective on life, one through which the song of the meadowlark or the arrival of spring is infused with significance. It is a lesson, he says, that he wished he had understood and appreciated before it was forced on him by his diagnosis. Viewers watch as he, his daughters, and his fiancée prepare for his death at home, where he is surrounded by their love. Other stories, called "A Different Kind of Care," "A Death of One's Own," and "A Time to Change," explore elements of the same point: the choices people have that can lead to a more peaceful death.

The broadcast was linked to a Website that encouraged further exploration. During the program, the screen highlighted what could be found there, including information on both practical and intangible matters, such as financial planning for terminally ill patients, various treatment alternatives, and "taking a spiritual inventory."

In conjunction with the series, the Foundation supported community outreach, hoping to spur about one hundred communities to take action locally. In fact, more than three hundred had some form of town meeting or other activity.

To bring about policy and regulatory change at the state and local levels, the Foundation funded a national program called Community-State Partnerships to Improve End-of-Life Care. Administered through the Midwest Bioethics Center in Kansas City, Missouri, the program awarded grants to promote policy change and support for high-quality, comprehensive palliative care in some twenty-one states, from Hawaii to Maine. The projects typically involve forming a broad-based coalition that determines priority issues, collects data, develops an action plan, promotes community discussion, suggests ways to improve palliative care, and

fosters dialogue within a religious community. In Kentucky, for example, Kentuckians for Compassionate Care, a partnership of more than fifty agencies, is identifying strategies to increase awareness among physicians, nurses, and the public about end-of-life care. Among its many activities, it has established a peer resource network and a toll-free help line for consultation and support to clinicians having difficulty managing pain and other symptoms in their terminally ill patients.

CONCLUSIONS

Palliative care comprises a number of elements—managing symptoms, communication between families and professional caregivers, spiritual and emotional support—but many consider pain management to be the first priority. A 1997 report by the Institute of Medicine emphasized that the number one fear that dying people had was the possibility of being in excruciating pain.¹⁰ Although experts say that pain can be controlled effectively in 90–95 percent of patients, each year a large number of Americans suffer pain unnecessarily as they die.

Palliative care proponents seek not only redefinition of appropriate end-of-life care but also shifted consciousness about the role of pain in medicine more broadly. This means measuring patient discomfort as a legitimate and standard practice as well as teaching health care providers the least intrusive and least painful ways to carry out various standard procedures.

A shift in the medical profession's attitude toward pain has, in fact, begun. In 1999, with funding from the Robert Wood Johnson Foundation, the Joint Commission on Accreditation of Healthcare Organizations, which accredits the majority of the country's medical facilities, developed new mandatory standards for assessing and treating pain. By January 2001, surveyors began scoring pain management programs and applying the results in the accreditation process. In 1999, the Oregon Board of Medical Examiners disciplined a pulmonary specialist for undertreating severe pain (for example, by refusing to prescribe morphine to an eighty-two-year-old with congestive heart failure). The board ruled that the physician had shown unprofessional conduct and gross and repeated negligence in undertreating six seriously ill or dying patients. From the point of view of palliative care advocates, this shift is a good beginning. But the goal is larger: to make pain a fifth vital sign along with temperature, pulse, respiration, and blood pressure; and to get medical schools and residency programs to focus on the pain experienced by patients.

It is too early to say if the changes more generally sought by those hoping to improve end-of-life care will

come about before the Foundation ends its substantial investment. But it is not too early to say that much has already been achieved in a short time:

- Surveys in 2001 from the American Hospital Association and the Center to Advance Palliative Care indicated that over 300 hospitals had palliative care programs, and more than 200 were planning to establish one.¹¹ This represents a relatively small percentage of the six thousand hospitals in the United States, but the growth has all occurred in recent years.
- The Last Acts campaign developed “precepts” for what good palliative care includes, such as respecting patients’ choices and providing comprehensive (including spiritual and emotional) care to patients and their families. The precepts have been endorsed by 162 organizations, as of May 2002.
- The National Cancer Policy Board of the Institute of Medicine recently stated that palliative care should be an integral part of good quality cancer care.

There is little doubt that palliative care and new approaches to understanding death have become legitimized quickly. As Judith Miller, a *New York Times* reporter, put it in a 1997 article on work by the Soros Foundation and the Robert Wood Johnson Foundation in this area, “Foundation giving has often helped create academic and public interest in a topic. ... But the sharp increase in research on death demonstrates the growing power of philanthropy almost to create an academic field.”¹²

Notes

¹ Morrison RS, Meier DE and Cassel CK. “When Too Much Is Too Little.” *New England Journal of Medicine*, 1996, vol. 335, p. 1755.

² Callahan D. *The Troubled Dream of Life: Living with Mortality*. New York: Simon & Schuster, 1993.

³ Lynn J. “Unexpected Returns: Insights from SUPPORT.” In *To Improve Health and Health Care 1997: The Robert Wood Johnson Foundation Anthology*. San Francisco: Jossey-Bass, 1997.

⁴ “Hastings Center Report Supplement,” Nov.–Dec. 1995, p. S12.

⁵ Rabow MW, Hardie GE, Fair JM and McPhee SJ. “End-of-Life Care Content in 50 Textbooks from Multiple Specialties.” *Journal of the American Medical Association*, 2000, 283(6), 771–778.

⁶ Rabow MW and McPhee SJ. “Patients’ Needs at the End of Life.” *Journal of Clinical Oncology*, 2001, 19(15), 3585.

⁷ See, for example, Ferrell, B. R. “Analysis of Symptom Assessment and Management Content in Nursing Textbooks.” *Journal of Palliative Medicine*, 1999, 2, 161–172.

⁸ Quoted in Carey B. “Last Days Needn’t Be Spent in Agony.” *Los Angeles Times*, Aug. 20, 2001.

⁹ Gibson R. “For Richer or for Poorer: Palliative Care for the Poor and Disenfranchised and the Role of Philanthropic Organizations.” Paper prepared for the Palliative Care Conference of the Royal Society of Medicine, London, Dec. 11–12, 2000, rev. Apr. 5, 2001.

¹⁰ Institute of Medicine, Committee on Care at the End of Life, *Approaching Death*, Field, M. J., and Cassel, C.K. (eds.). Washington, D.C.: National Academy Press, 1997.

¹¹ Pan CX and others. “How Prevalent Are Hospital-Based Palliative Care Programs? Status Report and Future Directions.” *Journal of Palliative Medicine*, 2001, 4(3), 307–308.

¹² Miller J. “When Foundations Chime In, the Issue of Dying Comes to Life.” *New York Times*, Nov. 22, 1997.