Promoting Excellence in End-of-Life Care
An RWJF national program

SUMMARY

Promoting Excellence in End-of-Life Care was a program to identify, promote and institutionalize care practices that allow seriously ill people and their families to approach the end of life in physical, psychological, spiritual and emotional comfort.

RWJF established a national program office at the Center for Ethics at the University of Montana at Missoula to manage Promoting Excellence and provide technical assistance to participating organizations.

The program's goals were to:

- Support innovative models of palliative and hospice care for people and in settings where they were underutilized or unavailable.
- Support initiatives to provide quality palliative care earlier in the course of illness, concurrent with life-extending care.

Key Results

Promoting Excellence supported:

- Twenty-two demonstration projects that created new models of palliative care.
- Four demonstration projects that tested models of delivering palliative care within hospital intensive care units.
- Eight disease- or issue-specific workgroups that brought health care leaders together to generate new ideas for their fields.
- Special Opportunities Fund grants that supported nine projects addressing gaps in knowledge or practice.
- A comprehensive communications strategy.
According to the national program office staff, *Promoting Excellence in End-of-Life Care* demonstrated that:

- It is possible to change the way health care professionals approach their work with people who are dying and their loved ones.
- Palliative and curative care can be provided concurrently.
- Projects integrating curative and palliative care can be sustained, replicated and expanded.

Staff at the national program office and participating projects reported the following key site results:

- Several hospitals, state agencies and hospice organizations changed their practices by adding palliative care staff to medical teams; using decision-making tools that address patient emotional and spiritual needs, as well as medical needs; and creating and utilizing new curricula for medical provider and community organizations. See *Program Results Report* on FOOTPRINTS in St. Louis for details.
- At least two projects increased access to palliative care by securing additional insurance coverage for those services.
- At least two projects demonstrated cost savings by reducing inpatient admissions, hospital stays and readmissions. See *Program Results Report* on Project Safe Conduct in Cleveland for more details.
- Several projects demonstrated that they improved patient outcomes by reducing pain, increasing the proportion of patients who die at home rather than in hospitals and serving patients with diseases, such as heart failure, that hospice has traditionally failed to reach. See *Program Results Report* on Pathways of Caring at the West Los Angeles Veterans Affairs Medical Center for more details.
- Costs did not increase in the *Promoting Excellence* projects, although costs of health care in the last six to 12 months of life remained high, commensurate with the complex needs of people who are seriously ill. In fact, in the projects able to track resource use or expenditures, total health care costs were moderately reduced, even with the provision of concurrent palliative and curative care.
- The eight workgroups each published *Recommendations to the Field* reports, some of which were adopted by medical specialty organizations as practice standards. See the *Program Results Report* on the workgroup on Amyotrophic Lateral Sclerosis.
- The *Journal of Palliative Medicine* published a 19-article series showcasing 17 *Promoting Excellence* projects and the national program office.
Funding

In July 1996, the Board of Trustees of the Robert Wood Johnson Foundation (RWJF) authorized up to $15 million to support *Promoting Excellence*.

THE PROBLEM

During the 1980s and 1990s, Americans began to be concerned about the long period of suffering many people endured before their deaths. "How people die remains in the memories of those who live on," said Dame Cicely Saunders, who founded the modern hospice movement in the 1960s.

Over the past several decades, many states passed laws to give people more say over how they die, allowing them to create living wills, durable powers of attorney and health care proxies. Hospice, which provides care aimed at ensuring the comfort and quality of life of terminally ill people, rather than at extending their lives, became widely recognized, and Medicare began to pay for hospice services.

Hospice care is part of a service continuum known as palliative care, which reaches more patients and their families over a longer period of time. According to the *Center to Advance Palliative Care* (established with funding from RWJF), palliative care programs generally address the physical, psychosocial and spiritual needs and expectations of patients with life-threatening illnesses at any time during that illness—even when life expectancies exceed the six months allowed by regulations governing hospice services paid for by Medicare.

Despite the growing attention to issues of death and dying, at the time *Promoting Excellence* began, many patients and their families had been left to make their own way through this dark and foreboding landscape. Hospice served fewer than 20 percent of Americans who died each year.

Most Americans in the early 1990s died in hospitals, often attached to machines in the intensive care unit (ICU), according to the RWJF-funded (1989 through 1994) Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). SUPPORT found that the one factor that most influenced where people died was not their wishes or that of their families, but how many empty hospital beds there were in the community. It also found that family members may not be present to communicate patient wishes and palliative care—to address emotional, social and spiritual needs—may be unavailable. (For more information on SUPPORT, see Chapter 8 in the RWJF Anthology, vol 1, 1997.)
Researchers at the University of Washington School of Medicine reported that:

- About half of patients who die in hospitals receive care in an ICU within three days of their death.
- One-third spend 10 or more days in the ICU during their final hospitalization.

Staff at the University of Montana's Center for Ethics, created in 1996 as the Practical Ethics Center to promote high-quality teaching, research and service on ethical dilemmas that face people in their everyday lives, identified other limits to the reach of hospice before the program began:

- Hospice had not been able to improve care for dying people in inner cities, rural areas and prisons—or on Indian reservations.
- Historically, hospice tended to focus on people with cancer, and had not reached people dying slowly of Alzheimer's disease, congestive heart failure or kidney failure, or those with longstanding serious mental illness.
- Little was known about the best way to care for the more than 53,000 children who died each year in the United States. Most of these children were treated in acute-care settings because pediatric hospice care was often unavailable. Family members may find it so painful to acknowledge that a child's illness is terminal that they are unable to participate in planning for palliative end-of-life care.
- Patients generally had to abandon life-prolonging care in order to receive hospice services. This meant that seriously ill people had to choose between care aimed at extending their lives and care aimed at alleviating pain and attending to their social, emotional or spiritual needs.
- Medicare required doctors to certify that a patient had six months or less to live before it would reimburse for hospice services, limiting the length of time in which people could benefit from hospice.

In short, as Joann Lynn, MD, MA, MS, concluded about her chapter on the SUPPORT study in To Improve Health and Health Care 1997 in the Robert Wood Johnson Foundation Anthology (1997), "Decisions are made very late in the course of the illness—a practice that risks some harm and precludes planning but protects most patients from having to consider the issues at all and spares families from confronting mortality until doing so is unavoidable."

Daniel Callahan, former president of the Hastings Center, a nonprofit research institute that focuses on bioethics issues, acknowledged the limits to what hospice had accomplished. "We thought we just needed reform," he said. "It is now obvious we need a revolution."
**CONTEXT**

RWJF’s engagement with end-of-life care began with the 1989 funding of SUPPORT, a $28-million, five-year study that looked at nearly 10,000 critically ill patients in five large hospitals, their families and the staff who cared for them.

The first phase of SUPPORT was descriptive, leading the researchers to conclude 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." *(Journal of the American Medical Association, 274: 1591–1598, 1995)*

The second phase of SUPPORT was an intervention designed to change that. The approach included intensive counseling for patients and families, frequent meetings with physicians and efforts to make the best possible information about prognosis and preferences available to the care team. In 1994, SUPPORT researchers informed RWJF that the intervention had failed to achieve its intended goals.

SUPPORT taught RWJF that marginal adjustments in approaches to end-of-life care were not going to be enough to overhaul the way in which care is delivered to dying people, and that more ambitious strategies were needed to help change social norms, professional values and social priorities. In an array of programs subsequently developed to improve care at the end of life, RWJF has pursued three strategies:

- **Professional education**, with projects that include:
  
  - Five grants to the Medical College of Wisconsin, totaling just under $1.7 million from 1998 to 2005, to train faculty to incorporate end-of-life training into their curriculum for internal medicine, family medicine, neurology and surgery residents. This was part of the college’s National Residency End-of-Life Education Project. See [Program Results Report on ID# 046547 et al.](#)
  
  - A $380,000 grant from 2001 to 2003 to the American Board of Hospice and Palliative Medicine to implement an accreditation process for fellowship training programs in palliative medicine. See the [Program Results Report on ID# 039835.](#)
  
  - A 1998 grant to the National Board of Medical Examiners to increase the quantity and quality of end-of-life questions on the medical licensing exam that all U.S. physicians are required to take. See the [Program Results Report on ID# 033887.](#)

- **Institutional change**, with projects that include:
  
  - A series of 38 grants totaling more than $23 million, starting in 1999 to the Mount Sinai School of Medicine in New York City to create the Center to Advance Palliative Care with the goal of integrating palliative care into hospitals. RWJF funding runs through June 2011.
• Public engagement, with projects that include:
  — The 1995 Last Acts® campaign, a coalition of more than 800 health and consumer groups that worked to:
    • Improve communication about death and enhance the capacity of consumers to make decisions about their own deaths.
    • Change the culture of health care institutions.
    • Change American culture and attitudes toward death and dying.
  — Starting in 1997, grants to the Center for Practical Bioethics (formerly the Midwest Bioethics Center) at the University of Kansas to operate the Community-State Partnerships to Improve End-of-Life Care national program—see Program Results Report on the program. Under this program, 21 states received grants to promote policy changes around end-of-life issues and high-quality palliative care.
  — A 2000 grant to Bill Moyers and the Educational Broadcasting Corporation to produce a four-part television program on the cultural, medical, ethical and spiritual aspects of death and dying in America. (See Program Results Report on ID# 038858, et al.)

PROGRAM DESIGN

The RWJF Board of Trustees authorized Promoting Excellence in End-of-Life Care for up to $15 million in 1996. The program's overarching purpose was to identify, promote and institutionalize care practices that allow seriously ill people and their families to approach the end of life in physical, psychological, spiritual and emotional comfort.

Promoting Excellence in End-of-Life Care was built on the belief that people who can benefit from palliative care should have access to it, whether or not they also choose to receive life-prolonging treatment. This is in contrast with the more typical "either-or" choice that many institutions require dying patients to make.

Promoting Excellence in End-of-Life Care aimed to identify, introduce and publicize changes in the structure, delivery and financing of health care that will allow more people to die peacefully and in accordance with their values and preferences.

The program's immediate goals were to:

• Support innovative service models for people and in settings where hospice care was underutilized or unavailable.
• Support initiatives to provide quality palliative care earlier in the course of illness, concurrent with life-extending care.
**Program Administration**

RWJF established a national program office at the University of Montana Center for Ethics to manage *Promoting Excellence* and provide technical assistance to participating organizations.

RWJF program staff chose Ira R. Byock, MD, as national program director. Byock helped found a hospice home-care program for low-income people in Fresno, Calif. He is a past president of the American Academy of Hospice and Palliative Medicine and a founder of the Missoula Demonstration Project, a community organization in Montana dedicated to creating a local model for end-of-life care that can be replicated on a national scale. See Program Results Report on ID# 36677 for more information. Byock also has written extensively about the end of life.

Jeanne Sheils Twohig was deputy director of the national program. Twohig established Montana's first Medicaid Home and Community-Based waiver allowing elderly people to remain in their homes and receive services paid by Medicaid. She directed the Partnership Health Center, a community health center for uninsured people in Missoula, which she also helped to develop.

A national advisory committee (see Appendix 1 for a list of members) provided program guidance and oversight to the national program office.

**The Program's Components**

*Promoting Excellence* was launched with three major components:

- Demonstration projects to create new models of palliative care (supported by RWJF with $12 million).

- A comprehensive communications strategy aimed at both professional and general audiences (supported by RWJF with $2 million).

- Special Opportunities Fund grants to address gaps in knowledge or practices as they were identified during the course of the program (supported by RWJF with $1 million).

**The Demonstration Projects**

The national program office released a Call for Proposals in May 1997 seeking letters of intent for projects to "improve access to comprehensive palliative care across a full range of clinical settings for patients with a terminal prognosis without limitations imposed by diagnosis, ethnicity, age or place of residence."
The national program office and the national advisory committee asked that proposed initiatives incorporate several features common to hospice and palliative care:

- An interdisciplinary approach (involving at a minimum, nurses, physicians, social workers and clergy).
- Clear and ongoing communication with patients and families.
- Clinical expertise in pain and symptom control.
- A philosophy that puts patients and their families at the center of the activities.
- Bereavement support to family members.
- Acknowledgement of the profoundly personal nature of the dying experience.

Some 678 organizations submitted letters of intent. The national program office and the national advisory committee invited 60 full proposals and received 58. In October 1998, they chose 22 initiatives to each receive $450,000 for up to three years (see The Initial 22 Demonstration Projects for capsule summaries and Appendix 2 for a list of the projects—with contact and other basic information about the grants).

RWJF planned to fund an independent research group to evaluate Promoting Excellence's impact on end-of-life care. Grantee organizations agreed to participate in the evaluation as a condition of receiving funds.

**The Communications Strategy**

RWJF and national program office staff built communications activities into every element of the program in order to share lessons and insights about end-of-life care via multiple media and with many different audiences. Vehicles for communication included the Web, professional journals, popular media, conferences and meetings.

Staff also encouraged sites to understand the power of stories about patients, families and their caregivers, and to find ways to tell those stories. Project sites received $15,000 communication grants, as well as other training and support, to help them share lessons from their projects and prepare articles for publication.

**Special Opportunities Fund Grants**

RWJF provided grants through the program's Special Opportunities Fund so that national program office staff could take advantage of new opportunities as they were identified by project sites, health care providers, policy-makers or the general public. Grants could be used for:

- Specialized assistance to demonstration sites in the areas of communications, program administration, and program or research design.
• Studies aimed at developing broader patient outcome measures to assess end-of-life experience and care.

• Planning for professional conferences and policy forums.

• Studies to advance the goals of Promoting Excellence that did not fit within the agenda of the demonstration sites.

Program Evolution

RWJF and the national program office intended Promoting Excellence to be flexible enough to adapt as the field changed and project sites gained experience in palliative and end-of-life care.

"We were encouraged by RWJF to learn as we were going, and we made a very strong effort to communicate at every step of the way," said program director Byock. "When we got the letters of intent, we read them and learned what the field wanted to do and where the field was ripe. Then, we broadened our program to reflect what the field said."

Based on early experiences, the national program office identified opportunities to embed end-of-life issues more broadly within health care institutions and expand Promoting Excellence by:

• Adding four demonstration projects focused on improving palliative care in hospital intensive care units (ICUs) to the original 22 sites, with $2.4 million from the RWJF authorization.

"The ICU was the belly of the beast where so many patients spend the end of their lives," said program officer Rosemary Gibson. The goal was to build on efforts that critical care leaders were already undertaking to create new delivery models for integrating palliative services into intensive care.

• Creating eight national peer professional workgroups to consider access to, quality of, and financing for palliative care among special populations (i.e., children); for specific medical conditions (i.e., end-stage renal disease); and in challenging clinical settings (i.e., critical care).

National program staff developed the topics for these workgroups from ideas that emerged in the original letters of intent and from workshops and other activities of the Special Opportunities Fund grantees. The topics also responded to stories in the media. For example, the Amyotrophic Lateral Sclerosis (ALS) Workgroup was created after "60 Minutes" aired a show about a man with ALS who had committed suicide. See the Program Results Report on the workgroup.
THE PROGRAM

The focus of all *Promoting Excellence* activities was to foster changes in the way America's health care system cares for seriously ill and dying people. "We helped the project sites realize that they were not doing small, local demonstration programs, but were trying to influence and move a field and to add new knowledge and tools and expertise," said RWJF's Gibson.

The Initial 22 Demonstration Projects

The objectives of the demonstration projects were to determine:

- Whether it was feasible to implement new models of palliative care acceptable to patients, families and health care providers.
- Whether new models affected access to, quality of and financing for palliative care.
- Whether new models could be sustained over time.

The demonstration projects, which were launched in November 1998, provided services in urban and rural settings, including hospitals, outpatient clinics, cancer centers, nursing homes, renal dialysis clinics, inner-city public safety-net facilities and correctional institutions. The national program office grouped these end-of-life care projects into three broad areas:

- Special populations.
- Patients with specific diseases and conditions.
- Challenging clinical settings.

All 22 projects:

- Collaborated with other organizations, such as the National Hospice and Palliative Care Organization, Blue Cross/Blue Shield, the American Correctional Association, universities, nursing homes and home health care agencies.
- Offered care coordination or case management, often provided by a nurse or social worker with special training in palliative care. Care coordinators monitored the status of patients and families, supervised the implementation of care plans, advocated for patients and maintained communication among partners.
- Developed and implemented standards of care for specific groups of people or for diseases to help clinicians make timely decisions, track patient progress and adjust care plans.
National program office staff provided ongoing training, technical assistance and evaluation assistance to the project sites. Staff also visited each site every year and sponsored three annual meetings:


Summaries of all 22 demonstration grants follow. Links to Program Results Reports and Sidebars provide more detail. The list of projects in Appendix 2 provides contact and other basic information.

**Projects Focused on Special Populations**

These projects created models of care for diverse special populations, including Native Americans and Alaskans, people with HIV/AIDS, people suffering from Alzheimer's disease, veterans, children, people with mental illnesses, low-income African-Americans and people living in rural or isolated areas.

- The Bristol Bay Area Health Corporation established *Ikayurtem Unatai (Helping Hands)*, which built on village networks to provide culturally based end-of-life care for people living in 34 Alaska Native villages in a 47,000 square-mile area of southwestern Alaska.

  Community health aides and village volunteers provided basic health care and volunteer services to dying residents. Doctors and nurses provided medical guidance to aides via telephone, e-mail and fax. See Program Results Report for more detail.

- *Pathways of Caring* at the West Los Angeles Veterans Affairs Medical Center:

  — Integrated palliative care with medical services for veterans with lung cancer, advanced congestive heart failure and chronic obstructive pulmonary disease who receive medical care at the West Los Angeles Medical Center.

  — Provided mechanisms for doctors and others at the hospital to talk frankly with patients about prognoses and care goals. See Program Results Report for more detail. Also see the sidebar, “A Story From Pathways of Caring: Model Program to Provide Comprehensive Palliative Care to Veterans.”

- The *Simultaneous Care* project, established at the West Coast Center for Palliative Education and Research, which is a part of the University of California at Davis School of Medicine:
— Used satellite communications to link university physicians with colleagues in three rural areas—Colusa, Tuolumne and Plumas Counties—in order to improve the quality of physician and home-care services.

— Provided palliative care services to women in California prisons, in collaboration with the California Department of Corrections.

— Extended palliative care to patients participating in clinical trials of new medications. This strategy challenged the notion that services focused on pain control, psychosocial concerns and end-of-life planning interfere with the efficacy of clinical trials.

*Palliative Excellence in Alzheimer Care Efforts (PEACE)*, an initiative of the University of Chicago Medical Center and Hospice of Michigan, offered palliative care to people with Alzheimer's disease and their families throughout the course of illness. PEACE operated in a primary care geriatric practice in Chicago and in nursing homes in Detroit.

Project staff helped patients and families create advance care plans, understand the progression of Alzheimer's disease and access community services. Nurse specialists helped coordinate care and reviewed records of interviews with patients and families to provide feedback to physicians. Over time, the nurses became more proactive in addressing the unmet needs of caregivers and patients.

*Louisiana State University Health Sciences Center* in New Orleans developed PalCare, which combined palliative care with aggressive HIV management for patients receiving outpatient treatment at the Health Sciences Center.

Patients tended to be stigmatized not only by an HIV diagnosis, but by some combination of poverty, drug use, mental illness and homelessness. PalCare staff worked with the outpatient primary care team, HIV inpatient care staff, hospice and home care services to assure seamless care to patients and family members.

*The Metro Suburban office of the Massachusetts Department of Mental Health* established *End-of-Life Care for Persons with Serious Mental Illness*. The project helped mental health care staff in suburban towns near Boston learn about and promote advance care planning for people with serious mental illness and to help hospice staff better address the needs of dying people with serious mental illness. Toward the end of the project, staff developed a communications campaign called "Do It Your Way" as a subset of its work.

Project staff developed tools to help providers evaluate the capacity of mentally ill patients to communicate their health care preferences, make medical decisions and complete advance care directives. Staff also taught hospice workers about mental illness and mental health care workers about hospice, creating a bridge between the fields.
• SSM Cardinal Glennon Children's Medical Center in St. Louis collaborated with the Saint Louis University School of Medicine to build and maintain FOOTPRINTS™, a statewide network of health care providers who care for terminally children and their families in their homes in Missouri. FOOTPRINTS participants received community-based hospice services, including medical, emotional and spiritual support. See Program Results Report for more details.

• The University of New Mexico Health Sciences Center worked with the Zuni Home Health Care Agency and the federally operated Zuni Comprehensive Community Hospital to create When Cure is No Longer Possible, a palliative care network in rural New Mexico. The project:
  — Created a palliative care network in seven rural communities in New Mexico with three distinct subcultures.
  — Integrated inpatient care of terminally ill patients at the Indian Health Service hospital with outpatient community care.
  — Created the Palliative Care Education, Research and Training Center as a coordinating body and clearinghouse of information. It also allowed rural providers to communicate with one another.

• The Medical University of South Carolina collaborated with the Center for Aging at the University of South Carolina and the Enterprise Community (a coalition of 18 neighborhood associations in Charleston, S.C.) to conduct Palliative Care Services for Urban African-Americans. Researchers conducted focus groups and structured interviews with African Americans living in 18 economically disadvantaged areas in Charleston. They wanted to understand how African Americans view death and why they tend to decline hospice care—and also learn about their preferences for end-of-life care.

• The Pediatric Palliative Care Project of Seattle's Children's Hospital Regional Medical Center used a decision-making tool to help families across the State of Washington plan care for children with progressive, potentially terminal illnesses.

  The project brought together Children's Hospital and Regional Medical Center, hospice organizations, the Washington state Medicaid agency and two large private insurers. Project partners developed procedures for flexible insurance benefits to ensure that Medicaid or private insurance would pay for needed services. See the sidebar, “A Story from the Pediatric Palliative Care Project.”

Projects Focused on Patients with Specific Diseases and Conditions

These projects created models of care for people with cancer, congestive heart failure, chronic obstructive pulmonary disease and end-stage renal disease.

• Hospice of the Valley and six managed care organizations in Phoenix created PhoenixCare to demonstrate the feasibility of caring for seriously ill people, adding
palliative care to the service mix and improving the quality of life without adding costs to insurers.

**PhoenixCare** served people who were still receiving active treatment for metastatic cancer, congestive heart failure or chronic obstructive pulmonary disease from one of the six participating managed care organizations in the Phoenix area. It featured a three-phase intervention:

— Patients entered the program with supportive care, including education about end-of-life decisions and help in managing disease symptoms.

— As needed, patients moved to enhanced care, where they received additional guidance about end-of-life decisions and symptom management.

— At the end of their lives, patients received the full complement of hospice services.

- **Baystate Medical Center** in Springfield, Mass., developed the **Renal Palliative Care Initiative** to integrate palliative medicine into the care of all patients with end-stage renal disease who were receiving services at Baystate Medical Center and eight area dialysis clinics.

  A team of nephrologists, nurses and social workers developed protocols to guide providers in joint planning with patients and their families on issues related to palliative care, ethical decision-making and the possibility of halting dialysis. The team taught all dialysis and transplant staff how to use these protocols.

- **The University of Michigan Comprehensive Cancer Center** in Ann Arbor, in collaboration with **Hospice of Michigan** in Detroit, designed a **Randomized Trial to Determine the Benefits of Earlier Hospice Care**.

  Researchers designed, implemented and evaluated the Palliative Care Program, which integrated hospice into the care plans of patients with advanced breast, prostate or lung cancer or advanced congestive heart failure, while life-prolonging treatment continued. A palliative care coordinator created linkages that helped to integrate essential elements of community-based hospice care with cutting-edge cancer treatment.

  Preliminary findings suggested that patients receiving the intervention:

  — Had lower inpatient costs, although the researchers believed those savings would prove to be negligible in a final analysis.

  — Had higher outpatient costs.

  — Stayed longer in hospice, but the difference was not statistically significant.

- **Educate, Nurture, Advise Before Life Ends (ENABLE)**, a project of the **Norris Cotton Cancer Center** at Dartmouth-Hitchcock Medical Center in New Hampshire,
brought palliative care into all stages of cancer treatment, beginning with the diagnosis, for people in Berlin, Lebanon and Manchester.

The project featured:

— A palliative care team, consisting of a pain management specialist, a psychiatrist or psychologist, a hospice or home health liaison, a social worker or case manager and a pastoral caregiver. Palliative care coordinators recruited patients into Project ENABLE and then coordinated their care.

— Educational seminars to help families and patients navigate the health care system, talk openly with physicians, prepare for advance care planning, understand the stages of dying and think about closure and the completion of life.

- Staff at Case Western Reserve University, in partnership with Hospice of the Western Reserve and the Ireland Cancer Center at University Hospitals in Cleveland created **Project Safe Conduct**. A multidisciplinary team housed at the cancer center offered patients palliative care services that allowed them to continue life-prolonging cancer care, including experimental therapy. See the sidebar, “A Story From Project Safe Conduct: Collaborative Interagency Program to Improve End-of-Life Care for Cancer Patients and Their Families.”

  The project also provided training about death and dying for providers and the general public. See the Program Results Report for more detail.

**Projects Focused on Challenging Clinical Settings**

These projects created models of care in settings that include a public safety net hospital, nursing homes and prisons. They also tested strategies for decentralizing care by providing clinical information online and clinical services in patients’ homes.

- **Cooper Green Hospital** in Birmingham, Ala., a public hospital serving predominantly low-income African-Americans, established **The Balm of Gilead**, which:

  — Created a 10-bed inpatient palliative care unit and a system to ensure that people would receive comprehensive end-of-life care regardless of their ability to pay.

  — Convened educational sessions and other community activities to promote institutional and community values that support end-of-life care.

  — Extended palliative care services into Birmingham-area hospice agencies and nursing homes.

Staff also created the CareSharing Initiative to engage local congregations and civic organizations in helping to set up the palliative care unit, visit families and host social events.

- **The Henry Ford Health System Enhancing Communication for Improved End-of-Life Care** project created a flexible array of services for patients in Southeast
Michigan with life-limiting illnesses who were covered by Senior Plus, the health system's Medicare managed care program. Under the project:

— Patients and their families explored care options via personal counseling and an interactive CD-ROM, "Completing a Life," which was created as part of the project.

— Staff recorded patient choices electronically, helping to ensure that all providers across the health system would know and honor their preferences.

— Clinicians throughout the system received in-depth training on how to discuss palliative care with patients and families and when to implement appropriate choices.

- **Mount Sinai School of Medicine Department of Geriatrics and Adult Development**, Franklin Health (a case management company later renamed ParadigmHealth) and Blue Cross/Blue Shield of South Carolina collaborated in creating **Integrated Case Management to Improve End-of-Life Care for Elderly Patients in Managed Care**. The project infused palliative care into case management services for high-risk homebound patients with life-limiting illnesses in South Carolina.

  Nurse case managers received training in how to assess and manage symptoms, manage the last hours of life, communicate with patients and provide feedback and recommendations to physicians. They also used computer-based treatment protocols to help them make decisions about treating pain and other symptoms.

- **Comprehensive Home-Based Options for Informed Consent about End-Stage Services (CHOICES)** program initially provided home-based palliative care to chronically ill people through the Sutter Visiting Nurse Association and Hospice and North American Medical Management. The program served residents of the East Bay near San Francisco who had home health coverage through Medicare managed care.

  When Medicare moved away from managed care, staff at Sutter redesigned CHOICES and created the **Advanced Illness Management (AIM)** program that serves people with end-stage illnesses or indications that they are failing treatment. Services include home-based palliative care, support in moving from curative treatment to end-of-life care, managing pain and symptoms and preventing unnecessary hospitalizations.

- The **University of California at San Francisco Medical Center** created the **Comprehensive Care Team Approach to Providing Palliative Care**, in which patients with congestive heart failure, chronic obstructive pulmonary disease or cancer simultaneously received palliative care and life-prolonging care.

  This project featured an interdisciplinary team of physicians, nurses and social workers who provided comprehensive care and family support to seriously ill outpatients near the end of their lives. Using a case management model, the program
drew heavily on local volunteer support services, faith communities and social agencies.

- The University of Pennsylvania School of Nursing and Genesis ElderCare (a long-term care provider) created the **Palliative Care Program for People Dying in Nursing Homes**. Six Maryland nursing homes tested ideas for embedding palliative care in their daily routines: Two homes served as control sites, providing care at a level above industry standards. At another two homes, staff received training in the concepts and practice of palliative care. In two other homes, staff received palliative care training and worked with a team of palliative care professionals to coordinate patient care, focusing on improving quality of life. See the sidebar, “A Story From a Palliative Care Program for People Dying in Nursing Homes.”

Project staff studied the effect of training and enhanced services on the experiences of patients and families, as well as on clinical outcomes and cost of care.

- The **Volunteers of America Guiding Responsive Action for Corrections at End-of-Life (GRACE)** project brought together corrections department officials in New York, North Carolina, Oregon and the Federal Medical Center for Women in Texas to create in-house hospice services for offenders living in their prisons.

Project staff also:

- Convened the GRACE Working Group of wardens, clinicians, pastors, attorneys and advocates to create standards of hospice and palliative care for people likely to die in prison.

- Created a resource center to gather, prepare and disseminate information about end-of-life care for prisoners and their families.

**Promoting Palliative Care Excellence in Intensive Care**

RWJF and national program staff designed Promoting Palliative Care Excellence in Intensive Care to bridge the gap between the aggressive medical care typically provided in intensive care units and the palliative care services many patients and families say they want.

To launch the initiative, national program staff:

- Issued a Call for Proposals in August 2002.

- Added two critical care specialists to the national advisory committee.

- Contracted with Seth Emont, PhD, a principal of the research consulting firm of White Mountain Research Associates and a former evaluation officer at RWJF, to help sites design and execute evaluations of their projects.
• Contracted with Lynn Spragens, owner of Spragens and Associates, a consulting firm specializing in financial analysis, to help sites analyze and understand their financial data and prepare business plans to assure their sustainability.

National program office staff received 242 applications, selected four projects and provided ongoing technical assistance, including four meetings for site staff:

• April 2–4, 2003, Newport, R.I.
• February 11–13, 2004, Mesa, Ariz.
• February 1–4, 2006, Big Sky, Mont.

Capsule summaries of the four intensive care unit demonstration grants follow. More detailed descriptions are available on the American Association of Critical Care Nurses website. Appendix 2 lists all the projects with contact and other basic information.

The four selected projects were:

- **Merging a Palliative Care Program with a Medical Intensive Care Unit (ICU).** To direct greater attention to the physical, psychosocial and spiritual issues facing patients admitted to the medical ICU at Massachusetts General Hospital in Boston (and their families), project staff at Massachusetts General Hospital and Harvard Medical School:
  — Created palliative care curricula and tools.
  — Trained palliative care staff about critical care medicine and critical care staff about palliative care.
  — Recruited and trained palliative care nurses to serve as "champions" for palliative care within the intensive care unit.
  — Instituted palliative care grand rounds.
  — Surveyed patients and staff, and extracted data from medical charts, to ascertain their knowledge of, and satisfaction with, services.

- **Implementing Palliative Care in an Inner-City Trauma/Surgical Intensive Care Unit.** The hospital at the University of Medicine and Dentistry of New Jersey Medical School in Newark developed an interdisciplinary model of palliative care initially centered in its surgical ICUs. Staff later expanded the project to the emergency department and step-down unit. The project:
  — Emphasized decision-making shared by families and staff, pain and symptom management and ongoing bereavement support.
— Trained doctors and nurses in palliative care and trained staff to provide 24-hour onsite support to medical staff.

— Introduced palliative tools and practices into existing clinical structures at the hospital. See the sidebar, “A Story of Implementing Palliative Care at an Inner-City Trauma/Surgical ICU.”

- **Implementing Palliative Care in Three Community Hospital Intensive Care Units.** Staff at Lehigh Valley Hospital and Health Network, in Bethlehem, Pa., and east central Pennsylvania, implemented and evaluated a palliative care model to support family decisions, improve communication with patients and families and assure continuity of care when patients left intensive care.

  The intervention was introduced in the medical ICUs of three community hospitals and later expanded to their surgical and trauma units. It employed a quality improvement format in which strategies were introduced, observed closely and then modified as needed. Project staff emphasized the medical, psychosocial and spiritual domains of ICU care by developing:

  — Care planning within 24 hours after a patient was admitted.
  
  — A formal approach to shared decision-making.
  
  — Interdisciplinary rounds, including a pastor, in which family members had the option of participating.

- **Introducing Interdisciplinary Palliative Care Services in Seven Intensive Care Units.** Researchers at the University of Washington School of Medicine created and implemented an interdisciplinary intervention to improve palliative care in seven intensive care units at Harborview Medical Center in Seattle.

  Project staff provided support and training to providers, interviewed staff to learn about barriers to palliative care, and offered timely feedback to clinicians. See the Program Results Report.

**Peer Professional Workgroups**

National program office staff convened eight peer professional workgroups, or “national learning communities,” to bring medical leaders together to generate new ideas for their fields:

- Amyotrophic Lateral Sclerosis Workgroup. See the Program Results Report.

- Children's International Project on Palliative/Hospice Services Workgroup.

- Cost Accounting Workgroup.

- Critical Care Workgroup.
End-Stage Renal Disease Workgroup.

Workgroup on Palliative and End-of-Life Care in HIV/AIDS.

Huntington's Disease Workgroup.

Surgeons Palliative Care Workgroup.

National program office staff selected workgroup chairs (see Appendix 3). The chairs and national program office staff then jointly selected the participants. "These are the leaders in their fields, the people who edit the textbooks and journals," said program director Byock. "We wanted them to come together and talk about how their fields deliver end-of-life care and what palliative care could offer their fields."

Each workgroup was responsible for:

- Conducting an environmental scan and describing the current state of palliative and end-of-life care in its field.
- Identifying gaps in knowledge and resources.
- Developing a Recommendations to the Field report identifying what needed to be done and how to do it.

National program office staff provided extensive administrative and logistical support. Under contract with RWJF, Heller Cunningham Consulting, a Brookline, Mass., firm specializing in small-group process, helped members structure and manage their discussions. Workgroups consisted of 15–35 members who met in person and via structured telephone conference calls over 18 to 24 months.

From the outset, the workgroups developed plans to disseminate their recommendations to health care providers, policy-makers and others. The national program office communications director assisted the workgroups in identifying audiences and venues for publication.

See the American Association of Critical Care Nurses site for a description of the Critical Care workgroup.

**Special Opportunities Fund**

Between 1998 and 2003, national program office staff used the $1-million Special Opportunities Fund to fund nine projects that addressed gaps in knowledge or practice in palliative care.

- *Talking Circles: Palliative Care Networks for Native Americans*, a national forum held in March 2001, was sponsored by the All-Indian Pueblo Council; the University of New Mexico Health Sciences Center; the Albuquerque Area Indian Health
Service; and the Palliative Care Education, Research and Training Center at the University of New Mexico. The forum allowed spiritual teachers, health care providers and administrators, and community elders from 18 states to meet for three days in Albuquerque, N.M., to discuss the need for palliative and end-of-life services for Native Americans.

- The Research Foundation of the State University of New York, The Life Institute and the Department of Veterans Affairs Health Care Network in Albany, N.Y., conducted a clinical trial involving 275 patients and 143 surrogates in six settings who were randomly assigned to the Advanced Illness Coordinated Care Project (AICCP) or usual care. AICCP participants met with a care coordinator for assistance with provider communication, care coordination and support. The researchers concluded that the AICCP improved satisfaction with care and helped patients develop and revise more advance directives sooner, without affecting mortality. This program may be delivered in a range of managed care, fee-for-service and group-model settings. (Findings published in the American Journal of Managed Care, 12(2): 93–100, 2006.)

- Providence Health System, Oregon Region supported a group of Catholic hospitals that comprised the Supportive Care Coalition in implementing CALL Care. CALL Care is an interdisciplinary model for providing comprehensive care to people with life-threatening illnesses that is used in 11 hospitals and long-term care facilities across the country.

- Rhode Island Hospital conducted a study entitled Measuring the Quality of End-of-Life Care in the Intensive Care Unit. No report is available.

- The National Hospice and Palliative Care Organization convened a two-day meeting of health care providers, researchers, spiritual leaders and others to create practical resources to care for children with life-limiting illnesses and their families. This laid the groundwork for the Children's International Project on Palliative/Hospice Services Workgroup, one of the eight peer professional workgroups.

- The University of Washington School of Medicine established the National Educational Resource Center on Palliative Care and HIV/AIDS, an educational resource and training program for health care providers. See the Center for Palliative Care Education for the curriculum.

- The Dartmouth-Hitchcock Medical Center surveyed critical care fellows to determine the type and extent of training they received in palliative and end-of-life care.

- The National Kidney Foundation studied the impact of a Michigan-based program called Peer Mentoring: Improving End-of-Life Planning for End-Stage Renal Patients and Families, which trains dialysis and transplant patients as volunteers to support other patients with chronic renal failure. The End-Stage Renal Disease Workgroup recommended that other such peer mentoring programs be developed.
The University of Washington School of Medicine convened a workshop in December 1998 to develop a research and education agenda to improve end-of-life care in intensive care units. See the Program Results Report.

The list of projects in Appendix 2 provides contact and other basic information.

**Evaluation Strategy**

Promoting Excellence and RWJF staff originally envisioned that an independent research group would be selected to evaluate the program. This approach proved infeasible for several reasons, according to the national program office director and deputy director:

- The end-of-life care field was young and evolving quickly. Few evaluators had expertise in the field and few data collection tools, research methods and protocols existed to conduct evaluations.
- The Call for Proposals had not specified evaluation requirements and national program office staff had not provided a structure that would allow the sites to collect data more readily in support of the research effort.
- Project staff did not have the time, resources or expertise to create and modify new models of care while also complying with the rigorous requirements imposed by an outcomes evaluation.

To support the external evaluation, all of the projects began to develop their own evaluation strategies, but they varied widely in approach and sophistication. Recognizing the limits of this approach, national program office staff convened a meeting with project staff in Washington in December 1998, entitled "Evaluating and Measuring the Impact of Our Work," to explore other options.

After that meeting, national program office staff, RWJF program officers and the national advisory committee decided to create an Evaluation Technical Assistance Program for the 22 sites, rather than require an external, research-focused evaluation.

**Evaluation Strategy for the 22 Demonstration Sites**

Melanie P. Merriman, PhD, a member of the Promoting Excellence national advisory committee, served as coordinator of the Evaluation Technical Assistance Program. Its goal was to integrate evaluation with technical assistance and feedback so that the sites could revise their project activities as they gained experience.

The key feature was one-on-one mentoring, provided by nine experts in quantitative and qualitative research in palliative and end-of-life care. See Appendix 3 for a list of mentors. Mentors were regularly available to project sites by phone and e-mail, and made onsite visits up to twice a year to assist with research design, tools development and sophisticated data analysis.
With the support of mentors from the Evaluation Technical Assistance Program, project staff:

- Created new tools or adapted existing tools in order to capture data about end-of-life care. For example:
  - Greg Sachs, MD, project director at the University of Chicago Medical Center's PEACE program, worked with a mentor at the Center for Bioethics at the University of Minnesota to review existing tools for measuring pain and to adapt them for use among terminally ill Alzheimer's patients.
  - Walter Forman, MD, project director for the New Mexico project, When Cure is No Longer Possible, and evaluation mentor Melanie Merriman, PhD, adapted quality-of-life questionnaires to fit local Zuni cultural mores.
- Collected data to measure patient experiences with pain, the quality of their relationships, and the extent to which patients felt their affairs were in order.
  - Staff at the Ireland Cancer Center in Cleveland asked patients about their level of pain, functional capacity, relationships and spiritual well-being. The recognition that patients were in more pain than the health care team had realized resulted in adjustments to palliative care plans.
  - Staff at the University of Chicago Hospital created after-death interview documents for use with family members to assess the quality of life for families whose loved ones had died of Alzheimer's disease.
- Ascertained clinicians' knowledge of palliative care.
  - In Alaska, staff at the Bristol Bay Area Health Corporation created tests to assess knowledge of palliative care among community aides before and after their training.
  - Project staff at the University of California at Davis School of Medicine assessed provider knowledge and beliefs about managing pain and other symptoms and their ability to talk with incurably ill patients about family involvement, bioethics and spirituality.
- Identified costs and use of palliative care.
  - The Department of Veterans Affairs, West Los Angeles Medical Center tracked the use of hospitalization and outpatient services by patients with chronic heart and lung diseases and lung cancer.
  - Researchers at the University of Michigan's Comprehensive Cancer Center and at the University of California at San Francisco used hospital data to compare the costs of caring for patients enrolled in their Promoting Excellence projects with the costs for control groups.
**Evaluation Strategy for the Four ICU Sites**

Based on lessons learned from the original demonstration sites, national program office staff specified evaluation requirements for the intensive care projects. All sites collected a core set of data, using common nurse and family surveys and a common tool to abstract data from medical charts. They used that data to evaluate:

- Changes in patient and family outcomes, including satisfaction with care.
- Communication between the patient/family and providers.
- Institutional change, such as the extent of continuity of care and use of quality improvement tools.

Evaluator Emont of White Mountain Research Associates helped the intensive care sites use the data collection tools and coordinated their evaluation efforts. In June 2006, Emont summarized the activities of the sites and described preliminary results in a report entitled *Promoting Palliative Care Excellence in Intensive Care Cross-Site Synthesis Report*.

Although these four sites collected common information, it proved infeasible to combine data or evaluate interventions across the sites. Problems arose because sites had small sample sizes, started and ended at different times and used imprecise measures of baseline and post-implementation dates. They were also inconsistent in their ability to collect and analyze data.

In addition, three of the four intensive care projects did not close until after the national program office closed and Emont's contract ended, further limiting the ability of staff to analyze or report on project outcomes.

**CHALLENGES**

The national program office faced two significant challenges:

- **The breadth of the program and diversity of the settings made it difficult for staff to provide "across-the-board guidance" and added significantly to the workload.** Hiring a communications director and a workgroup coordinator, and contracting for additional services, helped to ease the burden.

- **As noted in Evaluation Strategy, the projects could not be evaluated as originally envisioned.** The Evaluation Technical Assistance Program provided an alternative approach.

The demonstration projects also faced challenges operating their projects:

- **Engaging patients, families and providers meant overcoming Americans’ reluctance to address death and dying.** A cultural resistance to life's end is often reinforced by the highly technical medical environment, physician training and
tradition, the difficulty of saying "no" to medical interventions and the perception that palliative care means "giving up." In addition:

— Health care professionals generally lack education about end-of-life care and training to speak with patients and families.

— Native Americans, African Americans, Hispanic Americans and others who have been underserved by the health care system may view palliative care as a way of shortchanging them by withholding life-prolonging treatment.

- **Project design was not always realistic or clear.** The scope of some of the projects-involving combinations of clinical intervention, education, evaluation and dissemination-was too complex for available resources. For example:

  — One organization involved with the Comprehensive Care Team project in the San Francisco area requested reimbursement for services that project staff assumed would be provided at no cost. This confusion placed additional pressure on the limited resources available to the project.

  — Staff at the University of Chicago's PEACE project found that advance care planning did not prevent the need for large and unpredictable investments of staff time when patient complications occurred.

  — Many projects had difficulty collecting process and outcome data in busy clinical settings. Others found they had not clearly described their services or defined their criteria for patient enrollment.

  — Projects were not equipped to address many of the profound unmet needs of patients and families that emerged. Projects that served low-income people, including Balm of Gilead in Alabama, PalCare in Louisiana and Comprehensive Care Team at the University of California, San Francisco, were especially challenged.

- **Health care institutions are under stress.** Hospital mergers, service cutbacks, staff turnover, bureaucracy and the demands of busy clinical settings sometimes made it difficult for staff to meet goals. For example:

  — There were three chief executive officers at the Department of Veterans Affairs in Los Angeles during the course of the project.

  — Mergers at the Sutter Visiting Nurse Association and Hospice in the East Bay area near San Francisco, combined with nursing shortages and agency reorganizations, detracted from the energy available to develop CHOICES.

  — The program providing patients for the Henry Ford Health System's end-of-life project in Detroit ceased operations partway through the grant period.
The health care system is dynamic and unpredictable. Major external factors that affected Promoting Excellence projects include:

— Legislative changes and the decline of Medicare managed care created confusion and pressure for clinicians and administrators. For example, four of six physician groups that served CHOICES patients ended their Medicare component, reducing the pool of patients substantially.

— The Balanced Budget Act of 1997 and other federal laws sharply reduced reimbursement for home care services. Long-term care and hospice programs were pinched by static reimbursement and soaring pharmaceutical costs.

OVERALL PROGRAM RESULTS

Overall Results

National program office staff reported the following results in a report to RWJF and in interviews conducted for this report:

Promoting Excellence in End-of-Life Care demonstrated that it is possible to change the way health care professionals view death and dying. For example:

— The Surgical Palliative Care Task Force, originally a Promoting Excellence workgroup, now has permanent standing in the American College of Surgeons.

— The Amyotrophic Lateral Sclerosis Association and the National Hospice and Palliative Care Organization have jointly issued hospice-eligibility criteria for ALS patients based on information developed by the ALS Workgroup.

— The Supportive Care Coalition reported "During the [Promoting Excellence in End-of-Life Care] program's nine years of operation and beyond, its projects and initiatives will continue to positively influence the way Americans will be cared for through the end of life."

Collectively, the Promoting Excellence sites and initiatives, guided by the national program office, demonstrated that:

— Palliative and curative care can be delivered concurrently, at an earlier phase of the disease process and in mainstream medical settings. When the program started in 1997, many medical practitioners and institutions doubted that these two approaches to care could coexist.

— New leadership emerged in the palliative care field as project directors and site staff developed expertise and took on more visible roles within their institutions and in professional organizations.

— Projects integrating curative and palliative care can be sustained, replicated and expanded. All demonstration projects, other than those designed as time-limited...
research studies, continued after RWJF support ended. Many expanded to include more patients or broader geographical areas. See Afterward.

- **Costs did not increase in the Promoting Excellence projects, although costs of health care in the last six to 12 months of life remained high, commensurate with the complex needs of people who are seriously ill.** In fact, in the projects able to track resource use or expenditures, total health care costs were moderately reduced, even with the provision of concurrent palliative and curative care. The experience of these prototypical service delivery models suggests that creative, careful realignment of existing health system resources can improve the ability to meet patient and family needs without increasing costs. (From Byock I, Twohig JS, Merriman M and Collins K. "Promoting Excellence in End-of-Life Care: A Report on Innovative Models of Palliative Care." *Journal of Palliative Medicine*, 9(1): 137–146, 2006.)

- **National program office and project staff wrote several books, articles, monographs and reports.** See Key Communications Results, the National Program Office Bibliography, and the Project Sites Bibliography.

### Key Demonstration and Intensive Care Unit Site Results

National program office staff reported project results in two monographs—"Financial Implications of Promoting Excellence in End-of-Life Care" and "Living and Dying Well with Cancer"—and in a report to RWJF.

Director Byock and Deputy Director Twohig and other national program staff also reported results in two articles in the *Journal of Palliative Medicine*:


Project staff reported results in articles published in many issues of the *Journal of Palliative Medicine*, a peer-reviewed journal of the American Academy of Hospice and Palliative Medicine.

(See the Project List for additional results.)
**Changes in Practice**

Many sites expanded palliative care, and integrated it with other medical services. For example:

- **Baystate Medical Center in Springfield, Mass., incorporated features of the Renal Palliative Care Initiative into its ongoing operations.** As a result:
  - End-of-life care became a constant and high-priority agenda item at dialysis staff meetings.
  - After having access to evidence-based tools, dialysis staff demonstrated a greater ability to assess and manage pain and other symptoms.
  - The vocabulary of palliative care and advance planning became routine in the medical center and dialysis clinics.
  - The medical center and clinics held annual memorial services for staff and families of patients who died.
  - Physicians added discussions of quality of patients' death into their Morbidity and Mortality Meetings, which are regularly scheduled meetings at which doctors discuss aspects of death.

- **The Massachusetts Department of Mental Health, Metro Suburban Area, created an end-of-life committee that tried to keep terminally ill patients with serious mental illness in familiar environments as long as possible.**

- **Lehigh Valley Hospital and Health Network embedded palliative care into its ongoing operations:**
  - During their critical care rotation, resident physicians participated in seminars about communicating with patients and about the role of spirituality in care.
  - The registered nurse palliative care coordinator, a position created for the project, became a full member of the patient's multidisciplinary care team.
  - A group of physicians and administrators created an internal group to develop a vision for palliative care within the network.

- **The hospital at the University of Medicine and Dentistry of New Jersey incorporated several elements of its Promoting Excellence project into routine operations:**
  - The department of surgery created a division of surgical palliative care, thought to be the first in the country.
  - Palliative care became a standing agenda item in every monthly business meeting of the hospital's trauma unit.
— A member of the palliative care team routinely attended bedside rounds.

- The GRACE project in Virginia trained almost 200 prison inmates to serve as hospice volunteers helping to care for terminally ill inmates.

- The National Commission on Correctional Health Care adopted the GRACE project's standards for hospice care within prisons.

- Harborview Medical Center trained all intensive care unit staff in palliative care. It also created an onsite 24-hour consultation service to meet requests for information throughout the medical center. See Program Results Report.

- With its Safe Harbor Palliative Care Project, the Birmingham Veterans Administration Medical Center replicated Cooper Green Hospital’s Balm of Gilead. In addition, the University of Alabama at Birmingham created a palliative medicine section at its medical school.

- The Pediatric Palliative Care Project at the Children's Hospital and Regional Medical Center in Seattle created a comprehensive Decision-Making Tool and Care Plan. Prior to this project, staff used a tool that focused on medical needs and minimized social and financial considerations, and other issues relevant to the child and the family. See "A Story from the Pediatric Palliative Care Project."

**Expanded Insurance Coverage**

Some sites increased access to palliative care by working with insurance providers to cover palliative care services. For example:

- As a result of the Pediatric Palliative Care Project in Seattle, Regence BlueShield and Premera Blue Cross, two Washington state health insurers, expanded their benefit packages to include palliative care. The state also implemented a Medicaid benefit for children with life-limiting illnesses.

- Franklin Health began to use the protocols developed for the Integrating Case Management project in South Carolina in all of its work nationwide. The case management company also trained all of its care managers in their use.

**Cost Savings**

Some sites collected data to estimate or demonstrate cost savings from their projects. For example:

- The Pediatric Palliative Care Project in Seattle reduced costs. The project saved an average of $3,652 per month on the care of six high-cost children.

- At Pathways of Caring, which provided comprehensive palliative care to veterans at the West Los Angeles Veterans Affairs Medical Center, overall costs for the last month of life were $10,248 per Pathways participant compared with
$18,853 for the comparison group. This was one result of a number of differences, including:

- Pathways patients averaged 3.5 hospital days during their final month of life, compared with 8.2 days for the comparison group.
- Pathways patients averaged 0.4 days in intensive care during the last month of life, compared with 4.5 days for the comparison group.

- **The Integrating Case Management Project, targeted at elderly patients in managed care, saved money by reducing average inpatient days, admissions and readmissions.**
  - During its second year (2000), the project realized $22,000 in savings for each patient receiving case management.
  - During its third year (2001), the project realized $33,000 in savings for each patient receiving case management.

**Patient Outcomes**

Some projects demonstrated changes in patient outcomes. For example:

- **The PEACE program in Chicago reduced severe pain among participants.** According to a report by the national program office, some 23 percent of PEACE patients reported severe pain, compared with 44 percent of control group patients, according to project staff.

- **The CHOICES project in the East Bay area near San Francisco enhanced access to palliative care among patients with non-cancer diagnoses and among minorities.** It also helped patients to die at home. According to an article in the *Journal of Palliative Medicine* (Stuart, 2003):
  - Because CHOICES did not require patients to forgo treatment, it served people with diseases such as heart failure, whom hospice care often fails to reach. In 2000, 90 percent of CHOICES participants had a non-cancer diagnosis, compared with 15 percent of hospice enrollees in the same region.
  - Some 40 percent of CHOICES participants were people of color, compared with 18 percent of hospice enrollees.
  - Some 59 percent of the deaths among patients enrolled in CHOICES occurred at home. By contrast, 26.9 percent of all patients in California died at home, as did 24.1 percent of patients nationwide.

- **Helping Hands, Pathways of Caring, FOOTPRINTS™ and Project Safe Conduct all published project results demonstrating their increased use of palliative services.** The Site Profiles linked to the names of these programs provide more details.
**Educational Tools and Resources**

Among the many educational and training tools developed by project staff for providers:

- **A curriculum for providers describing Native American, Hispanic American and Anglo rural cultures.** Created at the University of New Mexico's Health Sciences Center's *When Cure is No Longer Possible*.

- **Palliative care curricula and postgraduate training courses for oncology specialists.** Created Project Safe Conduct at the Case Western Reserve Schools of Medicine and Nursing.

- **A community health elective course, taught by University of California at San Francisco faculty, for pharmacy, social work and medical students.** Students visited terminally ill patients as part of this training. Created at the Comprehensive Care Team in San Francisco.

- **"Standards of Practice for End-of-Life Care in Correctional Setting," a manual used by staff in correctional institutions.** Created at the Volunteers of America GRACE project.

- **A palliative care curricula for the medical intensive care unit.** Created at Massachusetts General Hospital and Harvard Medical School.

**Awards and Honors**

Several projects received citations and awards honoring their work, including five projects that received the "Circle of Life Citation of Honor" from the American Hospital Association. The Circle of Life Citation of Honor, a prestigious annual award that celebrates innovation in end-of-life care, was given to:

- **Project Safe Conduct** of the Ireland Cancer Center in Cleveland, 2002.
- SSM Cardinal Glennon Children's Medical Center in St. Louis, 2003.
- West Coast Center for Palliative Education and Research at the University of California at Davis, 2003.
- Renal Palliative Care Initiative of Baystate Medical Center in Springfield, Mass., 2003.
**Key Peer Professional Workgroup Results**

Program staff reported the following results in an article published in the *Journal of Palliative Medicine* (Byock et al., 2006) and in reports to RWJF:

- **Each workgroup wrote a Recommendations to the Field report.** See the Project Sites Bibliography.)

- **Several medical specialty organizations adopted workgroup recommendations.** For example:
  
  - The American Board of Internal Medicine Subspecialty Board on Nephrology added five questions about end-of-life care that had been developed by the End-Stage Renal Disease Workgroup to the nephrology board examination.
  
  - As noted, in 2001 the American College of Surgeons gave permanent standing to the Surgical Palliative Care Task Force, which originated as the *Promoting Excellence* Surgeons Palliative Care Workgroup. In 2005, the Board of Regents of the American College of Surgeons adopted the Workgroup's Statement of Principles of Palliative Care.

- **Workgroups created educational curricula and other tools for clinicians, practitioners and researchers.**
  
  - The Children's International Project on Palliative/Hospice Services Workgroup published "Compendium of Pediatric Care," a reference on pediatric palliative care available in the United States.
  
  - The Cost Accounting Workgroup produced a model template to guide finance administrators. The model captured the major medical services used at the end of life, and provided a grid in which an administrator can identify the resources used for each service, the per-unit cost and the total cost.
  
  - The Surgeons Palliative Care Workgroup produced a curriculum that incorporated palliative care concepts into surgical residency training.

- **Workgroups published in academic journals and websites, and presented findings at professional meetings.** For example, the Critical Care Workgroup produced a supplement to Critical Care Medicine entitled "Compassionate End-of-Life Care in the ICU."
Key Communications Results

To meet its goal of generating timely information about end-of-life care for health care professionals, families and patients facing difficult decisions and the general public, the national program office staff:

- **Created the Promoting Excellence in End-of-Life Care website** (no longer available). The website featured more than 340 tools and products developed by national program office staff, grantee organizations and workgroups. Among them:
  - Clinical care tools that address issues such as preparing advance directives, managing pain and coordinating care.
  - Educational tools, including curricula for clinicians, community groups and patients in areas such as breaking bad news, volunteer opportunities in palliative care and managing illness.
  - Organizational tools that offer guidance in enrolling patients, securing informed consent and assessing organizational capacity to provide end-of-life care.
  - General information, including profiles of funded projects, access to reports and monographs about the program, and access to CDs of conference presentations.

- **Provided guidance to help demonstrate site staff publish articles in general-interest publications and professional journals.** The emphasis was on bringing a human face to the work and offering lessons for professional and lay audiences. For example, they:
  - Worked intensively with project staff members and journal editors to prepare articles for the *Journal of Palliative Medicine*. As director of *Promoting Excellence*, Byock served as the editor of the journal's special series of 19 articles showcasing 17 *Promoting Excellence* projects and the national program office that captured the human, clinical and research facets of their work.
  - Sponsored a technical writing symposium. Staff from most of the *Promoting Excellence* sites attended the symposium, as did several dozen people from RWJF’s *Community-State Partnerships to Improve End-of-Life-Care* national program, the *Journal of Palliative Medicine*, and the *National Coalition for Cancer Survivorship*.

- **Spread information from the program through convening four special meetings, based on discussions with project sites about trends and issues of importance to them:**
  - "Integrating Cancer Care and Palliative Care: A Strategic Retreat," June 4–5, 2001, Chicago. Officials from 10 cancer centers, including four *Promoting Excellence* grantees, met to present and discuss strategies for providing end-of-life medical and palliative care.
— "Blue Cross/Blue Shield End-of-Life Forum," June 25–26, 2001, Washington. Senior representatives from several Blue Cross and Blue Shield health insurance plans and the Blue Cross-Blue Shield Association attended this meeting to exchange information about programs for people with terminal illnesses. National program staff prepared a compilation of innovative models of paying for palliative care, "New End-of-Life Benefits Models in Blue Cross & Blue Shield Plans," for the meeting. The Last Acts Finance Committee distributed it nationally.

— "Advanced Practice Nursing Meeting," July 9–10, 2001, Philadelphia. This meeting brought together a group of advanced practice nurses, who have masters or doctoral degrees and concentrate in a specific area of care. They discussed the state of palliative care advanced practice nursing, identified gaps in the practice and talked about strategies for the future. As a result of the meeting, a position statement, "Advanced Practices Nurses Role in Palliative Care: A Position Statement from American Nursing Leaders" was created. In addition, a monograph, Advanced Practice Nursing: Pioneering Practices in Palliative Care, was developed as a byproduct of the meeting.


● Created other communications tools including:

— Extensive print and electronic information-including newsletters, brochures and videos-for medical and palliative care professionals, general audiences and the media.

— Books, book chapters, articles, monographs and reports to the field.

— Training material for clinical personnel in print and electronic formats. See Educational Tools and Resources.

— An e-mail listserv for Promoting Excellence grantees and the national advisory committee.

— Presentations at national conferences. The 2003 and 2004 management and leadership conferences of the National Hospice and Palliative Care Organization featured a Promoting Excellence in End-of-Life Care track. Another Promoting Excellence in End-of-Life Care track was included at their clinical conference. National program office and project staff made presentations, which were later issued in a CD format.
Support to RWJF's Last Acts® program (later renamed Caring Connections: An Initiative to Promote and Expand Consumer Engagement in End-of-Life Care) by sharing information from projects and workgroups and inviting staff to Promoting Excellence meetings. The two programs collaborated in preparing publications, including a booklet entitled New End-of-Life Benefits Models in Blue Cross and Blue Shield Plans.

See the National Program Office Bibliography and the Project Sites Bibliography for a complete list.

**LESSONS LEARNED**

**Lessons for Managing National Programs**

1. **From inception, embed communication in every aspect of a program.** An emphasis on communication helped to spark interest and generate discussion in the health care field about ways to improve access to, and quality of, end-of-life care. (National Program Staff)

2. **To increase program reach, "find out what the field is ready to do, what issues are ripe," said Rosemary Gibson, program officer.** Creating and supporting small workgroups, comprised of leaders in the field and built around ideas in the unfunded proposals, helped to make the workgroups "one of the biggest leverages of grantmaking I have ever seen," according to Gibson. Providing specific guidelines and a timeframe in which to do their program was also essential. (National Program Staff, Program Officer/Gibson)

3. **Management should invest time in developing trusting relationships with staff of projects by:**
   - Recognizing site strengths and using them to inform the national program agenda and priorities.
   - Corresponding and communicating with project staff frequently.
   - Helping project staff create cohesive interdisciplinary teams.
   - Developing a detailed understanding of the projects, including local concerns.
   - Introducing project staff to others in the field who can provide assistance.
   - Fostering networks among principal investigators and key project staff across projects.
   - Recognizing that project staff may resist being told what to do and need to feel that the program's management is supporting them as well as monitoring them. (National Program Staff)
4. **Make evaluation an integral function of the grant from the program's inception, and not a program add-on.** In order to assess project impact, grantees need to understand what they are supposed to measure and how to do it. (National Program Staff)

5. **Use evaluations built around technical assistance to provide project staff with timely feedback.** "Technical assistance-centered evaluation really does work," said evaluator Emont. The Evaluation Technical Assistance Program helped project sites to develop evaluation capacity for future projects and to adjust their initiatives based on evaluation information. (Evaluator)

6. **Glean as much information and as many products from projects as you can before they receive all of their funds.** As projects near the end of their grants, it is harder to get their attention. (National Program Staff)

7. **Form partnerships to "carry the torch" when the program closes.** Management should develop a game plan for closing well in advance, including cultivating relationships with organizations that may be able to carry on the work of the program. (National Program Staff)

8. **Members of the program's management may take new jobs before the program closes and should use technology to maintain communication from diverse locations.** (National Program Staff)

9. **The impact of an initiative is weakened when the office managing the program closes before its grantees have finished their work.** The national program office closed its doors before the four projects focusing on integrating palliative care in ICU settings had completed their work. Thus the program—and the field—were unable to gain full benefits from their discoveries. "We did not have the opportunity to continue to work shoulder to shoulder’ with them to explore their results and collaboratively interpret the ramifications of their findings. Nor did we have the opportunity to synthesize the results across sites. Without this level of analysis and dissemination, the field did not learn all that it could have from the incredible efforts of the grantees and of the NPO." (Twohig/National Program Deputy Director)

### Lessons for Project Staff

10. **Find champions within the health care setting in which the palliative care project operates.** Medical institutions often do not view palliative care as a basic service, making it susceptible to cuts at times of financial pressure. Support at the upper levels of management is critical if the institution is to be willing to assume the organizational and financial risk of a complex undertaking. (National Program Staff, Project Staff)

11. **Begin initiatives with a manageable scope of work so that they can achieve early successes that garner support from clinical and administrative leaders.** Palliative care teams most readily become part of the institution's practice when they reduce the
burdens of clinicians. Teams also earn the confidence of colleagues by skillfully and reliably handling difficult, complex cases. (National Program Staff)

12. **Incorporate clinician education about end-of-life care into situations in which clinicians perceive a "need to know" and have a desire to learn.** Clinicians responded well to education that took place during morning rounds or regular conferences and to information presented in clinical meetings about patient morbidity and mortality. (National Program Staff)

13. **Identify strategies that respond to clinician priorities without adding new work.** "Make the right thing the easy thing to do" noted the national program's leadership. Physicians found that project-generated protocols addressing advance directives, patient preferences for spiritual counseling and pain measurement saved time and gave them useful information. (National Program Staff)

14. **Pay attention to the cultural traditions of ethnic groups.** Staff at Cooper Green Hospital's Balm of Gilead in Birmingham, Ala., created a culturally sensitive script for staff to use in talking with low-income African-American patients about advance directives. (National Program Staff)

15. **Create culturally relevant project titles that convey comfort, continuity, safety and control.** Some families were not comfortable enrolling in hospice programs that connoted imminent death. Project staff created titles such as Safe Conduct, ENABLE, FOOTPRINTS™, PEACE and Ikayurtem Unatai (Helping Hands). (National Program Staff)

16. **Acknowledge loss in ways that build a sense of community between staff and patients.** Project staff at the Renal Palliative Care Initiative at Baystate Medical Center in Springfield, Mass., held annual bereavement services and placed a rose and card at the entrance to the dialysis unit when a patient died. This tradition called attention to the passing of someone known by both staff and patients. (National Program Staff)

17. **Establish partnerships with entities that provide health coverage to patients.** Staff at the Pediatric Palliative Care Project in Seattle worked with private insurers to identify creative ways to pay for palliative care services within existing coverage guidelines. Staff also worked with state officials to enhance Medicaid coverage for palliative care services. (National Program Staff, Project Staff)

See also Appendix 5, "Ten Essential Ingredients for Building Successful Palliative Care Programs." This list was compiled by the national program staff, working with the demonstration sites.
AFTERWARD

The national program office closed on July 31, 2006.

The National Hospice and Palliative Care Organization assumed responsibility for most of the Promoting Excellence in End-of-Life Care website. The American Association of Critical Care Nurses assumed responsibility for the portion of the website devoted to intensive care. The 340 tools and products developed by grantees and workgroups will remain available on the Web.

In 2006, the American Board of Medical Specialties adopted palliative care as a new subspecialty in medicine (see chart of specialties with this subspecialty at the website). This means that new physicians will have the opportunity to have graduate medical education or choose a residency in palliative care. In addition, some 160 palliative care fellowships are in place around the country.

Progress for the Projects

All demonstration projects except those designed as time-limited studies continued their projects after RWJF funds ended and some projects expanded their reach. For example:

- The federal National Cancer Institute funded Helping Hands to establish a palliative care training program for health care providers serving Alaska Natives.
- FOOTPRINTS℠ in Missouri secured local foundation funds to expand the project elsewhere in the state.
- Project Safe Conduct in Ohio became part of the Ireland Cancer Center, which expanded it to include patients with gastrointestinal cancer and other malignancies.
- The PEACE project in Illinois continued within the University of Illinois Health System and expanded to include frail elderly patients with diagnoses other than dementia.
- PhoenixCare in Arizona continued with support from a Medicare Demonstration Project grant. The project now provides services to high-risk Medicare recipients who are not part of managed care programs.
- The Children's Hospital and Regional Medical Center in Seattle expanded the Pediatric Palliative Care Project to include an inpatient consult service and a formal palliative care residency training program.
- The Dartmouth-Hitchcock Medical Center's Norris Cotton Center in New Hampshire received funding from the National Institutes of Health to evaluate Project ENABLE.
- The West Los Angeles Veterans Affairs Medical Center received funds to conduct a four-year study based on the Pathways of Caring intervention. The medical center
expanded Pathways of Caring to include all patients with poor prognoses. See Site Story.

- The Sutter Visiting Nurse Association and Hospice received several grants to continue and expand its AIM program:
  - $300,000 from the Metta Foundation, matched by $300,000 from Sutter Health Center, to expand the Advanced Illness Management Program to additional communities in the San Francisco area.
  - $500,000 from Aetna Health Insurance to provide palliative care services to minorities living in the area.
  - $2.5 million from the Gordon and Betty Moore Foundation to reduce hospital readmissions and increase hospice referrals for appropriate patients with heart failure.

- The University of California at Davis School of Medicine received federal funds to continue and evaluate its Simultaneous Care project.

- The University of New Mexico Health Sciences Center developed a palliative care section in its department of geriatrics and created a palliative care fellowship program.

- The University of Pennsylvania School of Nursing expanded its "A Story from a Palliative Care Program for People Dying in Nursing Homes" to four additional nursing homes.

**Changes to the Field**

While the enduring changes in the field after the national program office closed are somewhat more difficult to capture, national program office staff reports that:

- Integrating palliative care into critical care has become a major focus of professional critical care medicine and nursing associations.

- Ongoing efforts are being made to incorporate end-of-life care into fields such as pediatrics, surgery, critical care and nephrology.

- Many of the projects succeeded in embedding cultural change within their institutions, making earlier and concurrent palliative and life-prolonging care more widely available.

- In 2003, Galen Miller, PhD, executive vice president of the National Hospice and Palliative Care Organization noted, "I consider the outcomes of the Promoting Excellence projects to be some of the most phenomenal in the business."
The West Los Angeles Veterans Affairs Medical Center is the largest in the Veterans Affairs (VA) system, and an easy place to get lost in—literally, and medically. A chart review of 50 patients diagnosed with inoperable lung cancer in 1996 showed that between diagnosis and death, not one of the 50 had seen a general physician even once. Fewer than half had seen the same physician more than twice after diagnosis, and a quarter had not had any follow-up care at all.

Pathways of Caring set out to close this gap with a case-management system meant to ensure not just medical continuity across providers and care settings, but a wraparound system of care that would address the concerns of patients and support their end-of-life wishes.

The focus was primarily on patients with lung cancer, advanced congestive heart failure, and chronic obstructive pulmonary disease, with the case managers—all masters-trained nurses—acting as advocates, educators, intermediaries and all-purpose problem solvers.

"The case management system is the motor for coordinating all these factors," says Ken Rosenfeld, MD, the Harvard-trained geriatrician who designed the program, but to an observer, the motor more closely resembles a compassionate heart.

"Each patient is completely different," says Tom Oleniacz, the program's bereavement counselor, who works closely with case managers Beverly Cummings, Leslie Evans and Linda Robinson, "and so are his needs." For one, it may be help with citizenship papers, or arranging to marry a long-time partner. For another, it's getting a new furnace installed before a return home from the hospital.

Heading down a hospital hallway Oleniacz stops to greet a vet waiting for an appointment. The man says he's doing well, because he feels he's got someone watching out for him.

"What exactly does Tom do for you?" he is asked.

"Everything I ask him to!" the man answers.
It turns out he is not kidding. Returning from a trip to Las Vegas, the patient was running low on oxygen, and got a ticket for speeding. "We wrote a letter that explained why he was speeding," Tom says, "and got the ticket reduced."

Listening to an exchange between Beverly Cummings, the program's original case manager, and Enrico Morell, its longest survivor, suggests both the tenor of the patient-team relationship, and the complexity of each vet's circumstances.

A handsome, soft-voiced man of 56, whom everyone calls Rico, Morell was diagnosed with congenital heart failure 10 years ago. When he enrolled in the program in December 2000, he was overweight, suffering from diabetes, was failing to take his medications consistently and had a life expectancy measured in months.

He lived at home with an aging mother, and was having difficulty remembering appointments or keeping track of symptoms.

"In the beginning, my thinking was, If I'm gonna go, I'm gonna go," said Rico. "There have been so many close calls. I didn't need to think about my direction."

A few years ago, while he was driving his car, Rico's blood sugar dropped and he lost consciousness. "It was perfect timing," he jokes. "An ambulance was passing by, and they just guessed what was wrong with me. Of course, my prayers are always answered," he says, with a playful smile in Beverly's direction. "When I woke up, there was Beverly floating in my room."

"Remember when you came in?" Beverly asks. "You said, 'When my heart stops, my heart stops'."

"I didn't want a pacemaker, or a transplant. I thought I'd bounce back."

"You didn't want to make the decision."

"I was worn down before the pacemaker. The doctor told me I probably had four months. I could feel the Reaper behind me."

Like many people, Rico also found it hard to think about writing an advance directive. "It was very difficult. I was fighting acceptance partly because I don't want to deal with the question—much less the answer."

"Advance directive is a process," says Jillisa Steckart, Pathways program administrator. "Some patients ask, 'How will I die?' Others say, 'How many months?' Staff will not give a precise figure—only 'months, not years,' or 'days, not months.'"
"We start by asking, 'What kind of a person are you? How do you want to hear news? Who do you want to be involved?’ Events often cause patients to reevaluate. It can be something like going to a brother's funeral.

"And every case is different. You can be terminal but not imminent. It's a trajectory. And it's not all about the medicalizing of death. It's often about basic things that might be missed—like 'I don't like to drink my food.'

"People fear the process. They fear the pain, the thought of being alone. They worry who will change their diapers. 'Is my body going to betray me?'"

"Each vet has a story," says Robinson. "By opening up to us, they open up to others. I'd like to say that it's because of us."

Morell is sure of it. "My attitude has changed because of the support I get here. Even if it comes down to the wire, I know there's always going to be someone there. Wars have been won with less."

A STORY FROM THE PEDIATRIC PALLIATIVE CARE PROJECT

If all that mattered to dying children and their families was an all-expenses-paid trip to the Grand Canyon or the World Series, it would be easy enough to ease the pain of young lives prematurely foreclosed.

But "dream come true" trips, however thrilling, are one-time events, a consolation prize for losing everything else. The palliative care program at the Seattle Children's Hospital has an entirely different focus: restoring to children and their families some measure of control over lives that are slipping from their grasp.

Two innovations were crucial:

- A new system to improve communication with children and their families.
- An imaginative partnership with insurers and the state Medicaid program to pay for palliative care services that ordinarily fall outside a traditional benefit package.

The communication piece, says Ross Hays, MD, the medical center's associate director, begins with "an honest discussion of what's going on, and what's likely to happen in the future. Sometimes, the medical team thinks the family is not ready to hear that nothing more can be done." Bringing everyone together in one room allows all the issues to be laid out, and all the unanswered questions asked.
An important element, says Hays, "is to ask families, 'What do you want? What do you need? How can we help make this easier for you?''"

At the end of the conversations, a document called the Decision Making Tool, or DMT, is created "which lays out clearly who will see to what planned action, by what date. It's reviewed by the family, signed by the physician and a copy is placed in the child's medical chart."

The DMT is not written in stone, says Hays. "It's meant to be revisited as conditions change. But it's not just the documents—it is the discussion that's important. We've paused long enough to ask you what your hopes and dreams are."

The shift in approach has played out in hundreds of small private choices:

- A 16-year-old girl who wanted to take a bubble bath every day because it alleviated her anxiety. "If she had not expressed that wish," says Hays, "we would not have had the line put under her skin. She took baths 'til the end of her life."

- An 11-year-old boy who opted out of treatment because it numbed his fingers and he couldn't play video games, one of his only remaining pleasures.

- A 17-year-old girl with liver cancer who took comfort, her mother said, in "calling the shots" about her care, and knowing she had the last word about how long it would continue. At one point, her mother remembers, "She turned to me and said, 'I'm tired of fighting. I'm giving up.' My response was, 'you're not giving up. You're taking control.'"

Equally important was helping families get needed insurance coverage. Most health care plans require a prognosis of less than six months of life to qualify a patient for hospice care, but many of the children for whom palliative care services were appropriate could live longer. "There was a lot of tension in the first meeting with insurers," says Nanci Villareale, who led early discussions with insurance representatives. "Companies thought we were going to ask for new benefits, but what we asked for was flexible use of [existing] benefits."

"A benefits package is a like a house," adds Hays. "We weren't asking for the house to be bigger—but couldn't we divide up the rooms differently?"

It turned out that insurers had been talking about this need for years. "We ask the question: 'Can a patient get the same safe level of care in a different setting?'' says Pat Emerick, who represented Regence Blue Shield, one of two insurers who participated in
the initial discussions. (The other insurer was Premara.) "And then we see what we can do."

Initially, children eligible for flexible benefits were those whose death within two years would not be considered a surprise. That definition proved problematic. "When we first started out," says Emerick, "we could not get a single parent to sign up, because they couldn't accept the idea that their child might die within two years. Even if they're watching the child die in front of their eyes, it's often very hard to accept." Eligibility was redefined in a more open-ended way: eligible children became those who had a "potentially life-limiting" illness.

In some cases, benefits were "flexed" from the home health benefit package, in others from traditional hospice benefits. Emerick explained, "If it's cheaper to get a medication infusion at home instead of in the hospital, for instance, we could authorize a home infusion agency to go out and give the medication even if the patient didn't have home infusion benefits."

Respite care was pieced together when the situation warranted it. "We had a single mom with two children, one of whom was very ill," recalls Emerick. "The mother really soldiered on, in the kind of situation that makes you wonder how she got through the day, but the younger child was struggling because all the attention was going to his sibling. We were able to put together enough days of respite care to make it possible for the mother to take her son to Disneyland."

"We went from patients hating the insurance companies in the beginning to sending pictures to the case manager at the end" says Villareale.

"As a social worker," says Emerick, "I often felt like the fairy godmother at Sleeping Beauty's christening. I can't take the curse away, but I can make it a little better."

A STORY FROM PROJECT SAFE CONDUCT: COLLABORATIVE INTERAGENCY PROGRAM TO IMPROVE END-OF-LIFE CARE FOR CANCER PATIENTS AND THEIR FAMILIES

"I start by asking, 'Tell me what your day is like? What time do you get up? Do you feel rested? What do you do for breakfast, lunch, dinner?'

"You have to walk them through the day," says Polly Mazanec, a nurse practitioner who is part of the three-member Safe Conduct team at the Ireland Cancer Center in Cleveland.
"They don't think we want to know that level of detail, but that's how we find out what kind of support they need."

"I ask specifically about aches, pains, shortness of breath, whether they are sitting in a chair to sleep. You can't assume they are taking the pain medication. You have to ask to find out. 'Were you able to get that prescription filled?'"

Sometimes it is the most silent sufferers who have the greatest cause to complain. A large portion of the Safe Conduct team's efforts takes the form of gentle and persistent probing for problems that patients choose to keep to themselves.

Why? Some, Mazanec says, are afraid that a complaint will lead to no treatment, either because the symptoms they are keeping to themselves will reveal that their case is hopeless, or because they will somehow appear ungrateful for the care they have been receiving.

"It's also hard for patients to process side effects, which are a constant reminder that they are fighting for their lives," says Diana Simic, the social worker on the interdisciplinary team. "They want to bracket the experience when they walk through the door. They return home and they want to forget about it.

"It's also generational. I hear older patients say, 'Ah, honey, you're so busy. You look so tired.' Partly it's a way of giving back, and partly it's a way of minimizing their problems. There is a profound sense of dependence, on caregivers, friends, neighbors, which is very hard to accept, especially for women."

There is a similar reluctance among many patients to talk frankly about pain. Fears about addiction, unhappiness over side effects, unrealistic expectations and finances are all common. In fact, says, Mazanec, who is also a longtime oncology nurse, "The easiest part of pain management, if you know your stuff, is the manipulation of the drugs. The hardest part is all the other things that go on."

As the team met to review current cases, it was clear there is no shortage of "other things" that interfere with patients' well-being. One woman with nerve pain seemed to have the appropriate medication, except it turned out she couldn't afford it.

"It was rent, or drugs," says Elizabeth Pitorak, director of the Hospice Institute of Hospice Western Reserve, and co-designer of the Safe Conduct project. "Polly thought of methadone, which is much cheaper—about a dollar a day—and it worked. Often a doctor will say, if he can't afford drugs, let's give him a patch, but that's only a little bit cheaper, not much of a help."
A young man with liver cancer was suffering chronic pain in his liver, stomach and shoulder, but a history of chemical dependency had him worried about becoming re-addicted. Unemployed, and with a $30 co-pay, he said he couldn't really afford the pump system he'd been using for pain medication, but when Polly recommended methadone, he balked. On top of all this, he was newly engaged and did not want to take an antidepressant because of the sexual side effects. His fiancée wanted to get married soon, he said. "Next spring, if I'm still alive."

"He's got a lot of issues to deal with," says Simic. "Diabetes, pain, sex, money. When a patient starts to lose control over everything in his life, what he can control is what he puts in his mouth. I don't think it's always about cost. If there is something we can give him that he needs," she suggests, "perhaps he'll relinquish control over his medications."

The man is experiencing impotence that the team believes to be related to his disease, and suggests that he try Viagra, hoping that having some power over his body again will improve his willingness to be treated for pain.

Discussing another patient, the subject shifts to how to help a family prepare for the end. Stephen Adams, an ordained Presbyterian minister and the third member of the Safe Conduct team, describes a typical exchange. "The son-in-law asked, when the father was not there, 'So how long will this last? Does Tarceva work?' The daughter shot him a look, meaning 'I don't want to know.'"

"One of our jobs is to find out how a family copes," says Simic. "What is the support system? What do they want to know?"

"I pose it as an open-ended question for patients," says Adams, who has been involved with end-of-life work for almost 14 years. "What is your image of death, and beyond death?

"Sometimes they say they don't want to talk about it. After, they do. Asking gives them permission. Every individual has to explain to us what is their language, what's safe for them."

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**A STORY FROM A PALLIATIVE CARE PROGRAM FOR PEOPLE DYING IN NURSING HOMES**

"Two years ago, if someone had asked me if he was going to die, I would have run out the door and gotten someone else to talk to him," said Ronnie Knopp, LPN, a unit manager at the Pines Nursing Home in rural Easton, Md., and for the last two years, the home's palliative care leader. "Now I say, 'Yes, you are, and so am I.'"
If anything defines the transformation created by the palliative care initiative at the Pines—one of six nursing homes in the Genesis Elder Care system that participated in the project—it is the shift in the way staff members view their role in caring for patients, and the results of their greater involvement.

"When you bring up the palliative care concept," says Neville Strumpf, PhD, RN, director of the Center for Gerontologic Nursing Sciences at the University of Pennsylvania School of Nursing, and co-designer of the project with Genesis medical director Howard Tuch, MD, "the first thing people think is that you are suggesting they're not giving good care. The trick is convincing them that they are providing care, but a different kind of care."

Key to the investment in making the new approach work at Pines was the top-to-bottom education in palliative care principles that everyone on staff receives, "including the kitchen staff," says Stacey Radcliffe, who has been the administrator at Pines for 10 years. "They have a nurturing role to play. After they received their training, they said, 'We could put together a coffee service.' They also designed a new menu for the hospice patients." The training is important in terms of adding to the staff’s repertoire of resources, but also, says Strumpf, because it "breaks down some of the myths about what is clinical, what is professional."

The program model focused on advance care planning, pain and symptom management, and psychosocial issues, but the practical applications were as varied as individual patients' needs, and as imaginative as the situation warranted. Traditional visiting hours were eliminated, so "family and friends can come and go," says Radcliffe.

"Going into a nursing home represents the loss of many things. We urge people to bring in mementoes, DVD players, TV's with remote, sleeper chairs, whatever makes them comfortable," says Radcliffe.

Early in 2005, Knopp came to Radcliffe to talk about a 38-year-old patient plucked from his former life by an inoperable brain tumor. Previously, Knopp had arranged for him to accompany his former work colleagues to an Orioles game, and to attend a company picnic.

Now, she said, he really needed to see more of his kids, ages 7 and 14. "Can we have a sleepover?" she asked. A nurse's assistant had already volunteered to come in from 11 p.m. to 7 a.m. to help. "OK," said Radcliffe. "Why not? Who are we to say a patient's children can't stay overnight? Our job is to care for the patient. That helps him."

More typical interventions focus on pain and symptom relief, and on helping families through the dying process.
"If nurses or assistants see that any patient is in pain, they are to act on it," says Michael Crowley, MD, the long-time medical director at the Pines. "There is greater initiative on the part of the staff as a result, and more integration of care."

Sometimes, the most important intervention can be helping patients to acknowledge a new reality. "We had a patient who was rolled in the door screaming," says Joan Gannon, RN, director of nursing. "He'd had radiation at a cancer center and his backside was raw from the radiation."

From the man's discharge papers, it was clear that his prognosis was poor, and the treatment essentially pointless. "We sat down and talked with the man's wife first, and explained that his condition was poor. She said we should talk to her husband, so that whatever time they had left together, he could spend it comfortably, without pain. When we talked to him, he said, 'Thank you.' He was doing [the treatment] for her."

Nursing assistants, who often have the most intimate daily contact with patients, attended a seminar on alternatives to pain medication, and the staff put together a comfort supply cupboard for families stocked with lotions, grain pillows, anti-stress comfort wraps that can be frozen or heated, music, literature on what families can expect at the end, stuffed animals and scent stones. "You hear kids saying, 'Grandma Stinks,' says Knopp. "That's true. So what can we do to make the kids feel better?"

By being more proactive themselves, the staff has found they can help patients and family members who are paralyzed by fear or grief. "I had a family member say that he couldn't sit with his wife when she was dying," Radcliffe recalled. "He said, 'I am not a nurse. I don't know what to do.' Ronnie comes in, and she says, 'Here's some lotion—we're going to rub her back, then her legs.' 'You know what?' he said. 'It was better.'"

In turn, by asking more of the staff, the Pines has developed an unusually seasoned one. "Staff turnover is a big problem in nursing homes," Strumpf points out. "One reason the Pines is so successful is its low turnover."

"We haven't always been the facility of choice," says Radcliffe, referring to the Pines' earlier reputation within its rural community—the kind of place where staff members run into their patients' families regularly at PTA meetings, the market and the hairdresser. "We chose to start changing our reputation one patient at a time, and we have."
A STORY OF IMPLEMENTING PALLIATIVE CARE IN AN INNER-CITY TRAUMA/SURGICAL INTENSIVE CARE UNIT

The Trauma/Surgical Intensive Care Unit (SICU) at University Hospital in Newark is the sort of place people land without warning: a gunshot wound late at night; a car accident on the way home from the movies. Many of the patients are young. Virtually no one comes in carrying an advance directive.

"As a trauma surgeon," says Anne Mosenthal, MD, head of the unit, "I imagined saving everybody's life. But people come in and a lot of them die—or arrive dead. A big part of my life is going out to tell a family their son just died. Nobody ever taught us how to do that."

Dealing with the fallout of life and death traumas—with stunned, often angry families suddenly forced to make painful decisions, and with critically ill patients who may not be able to communicate their wishes, or signal their need for pain relief—is the focus of the interdisciplinary palliative care program designed by Mosenthal and co-principal investigator Pat Murphy, and it has changed the culture of the SICU.

"Traditionally," says Pat Murphy, who started the hospital's first bereavement program 20 years ago, "'going for broke' is the ethos on the SICU. Trauma surgeons tend to think, let me try one more thing, maybe it will work. Sometimes the most valuable service they can provide is witnessing a good death."

Within 24 hours of a patient's admission, Susan McVicker and Janet Harris Smith, who are family support and bereavement counselors, meet with the family to answer their questions. "The first thing we ask," says Smith, "is 'What do you need?'"

Within 72 hours, a second meeting brings the family together with a physician, nurse and one of the support counselors to make a comprehensive plan that addresses care goals, the patient's spiritual or religious needs, the family's emotional concerns, cultural preferences and any other issue of importance to the family.

Trauma patients make up roughly 60 percent of the patients on the unit; the remainder are liver transplant candidates hoping to get well enough to qualify for surgery, and a smaller number of post-transplant and other surgical patients in crisis. Most of these patients, says Dorian Wilson, MD, head of UMDNJ's liver transplant unit, also come in without an advance directive (AD).
"During the admission process, we ask, have you got an AD? The next step is, what are we going to do about it? Even the families who look like they are going to pounce on you are often ready more than you think they are. I used to think, 'they won't be able to handle it,' but they can if you help them."

"People don't really know what predictions signify," says McVicker. "The physician will say, 'His eyes are open,' and they expect a great outcome. We tell them to ask the doctor what survival means. They hear from physicians that they won't do resuscitation. They see resuscitation on ER. You have to explain: 'Resuscitation won't bring your parent back from cancer.'"

"I had a 45-year-old die today at 3:30," Smith recalled at the end of a long day on the unit. "He had a very clear advance directive, but a nurse had put a face mask on him after extubation. Once you put it on, it's emotionally very hard to take it off. I was able to say to the family, 'You are honoring your father's wishes, making a gift to him, just as he gave a gift to you by telling you clearly what he wanted to have happen.' That helped, but the 15-year-old said, 'It's not fair.' And I thought, you're damn straight."

The same day, less than 24 hours after a 19-year-old man was brought in with a gunshot wound in the back of the head, SICU chief surgeon David Livingston, MD, McVicker and Reverend George Blackwell, an ordained Baptist minister and director of pastoral care for the hospital, met with his angry, extended family crowded into a small conference room.

"His Mom and aunt were there," recalled Livingston, "and I basically said, 'I don't know what you know but I'm going to start from the beginning. He wasn't breathing, he wasn't moving, when the paramedics found him.' You don't say 'alive.' The mother asked me, Is he brain dead? And I said, not yet. But he probably will be in the next couple of hours."

From the medical professional's perspective, brain death is an incontrovertible matter. To families in shock, it is often just incomprehensible. "Almost no one gets it the first time," says Rev. Blackwell. "To hear that this young person who looks fine is dead—it just doesn't compute. What we've learned is that the earlier we start, the easier it is to make a difference. It's a process."

Recognizing when it's time to stop treatment is something most surgeons have to learn, says Livingston. "There's a difference between when you are doing something for a patient, and when you are doing something to a patient, but that transition is subtle. Nurses take the brunt of this. They recognize when patients are being tortured. They also have seen patients come back from incredible situations."
The program's innovations have affected the unit's nursing staff. "I'm not saying that before we were not sensitive," said Shyla Joseph, a seven-year veteran on the unit, "but now they make more resources available."

**Pain management is one big change.** "If the patient is alert," says Ann Lopez, who has been in the SICU for three years, "we ask, 'Are you in pain right now—on a scale of 0–10.'

We have a separate assessment for patients who cannot speak: we look for grimacing, and restlessness. Usually there are standing orders for morphine, or if they can swallow pills, Percocet. Before, if a patient asked for more painkiller, we used to have to say, 'It's not time yet.' Now we've been taught you have to address pain no matter what. Right then. If the first med doesn't work, you have to give them something that does, until their pain is relieved."

Another small change that has made a big difference is the shift to unrestricted visiting hours. Before, says Mosenthal, "We had lots of problems with families getting angry about visiting hours. Now there is open visiting 24 hours a day and it has been fantastic."

"Everybody can come now," says Joseph, "even small children. The family support team prepares them. Now families have more information, they know what each machine is doing.

They ask us, 'Once you pull the plug, he's going to die?' They ask, 'Is he going to suffer?' We say, 'We'll bring medication for pain, and he'll slip into a deep sleep'. Here we bring patients back to life who are dead, but not all the time. I think this is a good place to die, too."

La Vern Allen, a nurse who has been on the unit two-and-a-half years, agrees. "The program has made our job easier. It's difficult when it's just you and the families and they are upset with you for breaking bad news. Now we can call the team to back us up. We've learned from them to be more conscientious in what you say—and you say it with more compassion. You keep it in the back of your mind: If that was you, how would you want bad news to be told?"

---

**Prepared by:** Mary Nakashian  
Reviewed by: Karyn Feiden, Marian Bass and Molly McKaughan  
Program Officer: Rosemary Gibson  
Project Director: Ira R. Byock
APPENDIX 1

National Advisory Committee

(Positions at the time of the program)

Ellen L. Stovall, Chair
President and CEO
National Coalition for Cancer Survivorship
Silver Spring, Md.

Richard Della Penna, MD
Director, Aging Network
Kaiser Permanente Continuing Care Services
San Diego, Calif.

Brent Eastman, MD
Chief Medical Officer and N. Paul Whittier
Chair of Trauma
Scripps Memorial Hospital La Jolla
Scripps Health
San Diego, Calif.

Kathy Faber-Langendoen, MD
Director, Center for Bioethics and Humanities
SUNY Upstate Medical University
Syracuse, N.Y.

Melanie Pratt Merriman, PhD, MBA
Touchstone Consulting
North Bay Village, Fla.

Steven Miles, MD
Professor of Medicine and Geriatrics
University of Minnesota Center for Bioethics
Minneapolis, Minn.

Laurence J. O'Connell, PhD, STD
President and CEO
Park Ridge Center
Park Ridge, Ill.

Joseph F. O'Neill, MD, MPH
President and CEO
Immune Response Corporation
Carlsbad, Calif.

Richard Payne, MD
Director, Institute on Care at End of Life
Duke University Divinity School
Durham, N.C.

Carol Raphael, MPA
President and CEO
Visiting Nurse Service of New York
New York, N.Y.

R. Knight Steel, MD
Chief of Geriatrics and Director of Home Care Institute
Hackensack University Medical Center
Hackensack, N.J.

Ann Thompson, MD
Director, Pediatric ICU
Children's Hospital Pittsburgh
Pittsburgh, Pa.

Diana Wilkie, Ph.D, RN
Professor and Harriet Werley Endowed Chair for Nursing Research
Department of Medical-Surgical Nursing
College of Nursing
University of Illinois at Chicago
Chicago, Ill.

Donna L. Wong, PhD, RN, PNP, CPN
Nursing Consultant and Associate Professor
University of Oklahoma
Oral Roberts University
Tulsa, Ok.

Laurie Zoloth, PhD
Professor, Medical Ethics and Humanities Program
Northwestern University
Chicago, Ill.
APPENDIX 2

The Initial 22 Demonstration Sites

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

Projects Focused on Special Populations

Ikayurtem Unatai (Helping Hands): Establishment of a Culturally Sensitive Rural Hospice Program for Alaska Natives

Bristol Bay Area Health Corporation
Dillingham, Ala.

Amount: $449,513
Dates: October 1998 to May 2002
ID#: 035496

Contact
Robert Swope, Project Director
(907) 842-9473
bswope@bbahc.org

Pathways of Caring: Model Program to Provide Comprehensive Palliative Care to Veterans

Brentwood Biomedical Research Institute, Department of Veterans Affairs
West Los Angeles Medical Center
Los Angeles, Calif.

Amount: $450,000
Dates: October 1998 to April 2002
ID#: 035493

Contact
Kenneth E. Rosenfeld, MD, Project Director
(310) 478-3711
Kenneth.Rosenfeld@med.va.gov

Simultaneous Care: Program to Improve End-of-Life Care for Isolated Rural Populations and Female Inmates

West Coast Center for Palliative Education and Research
University of California at Davis School of Medicine
Davis, Calif.

Amount: $447,434
Dates: October 1998 to May 2002
ID#: 035490

Contact
Frederick J. Meyers, MD, Project Director
(916) 734-8596
fred.meyers@ucdmc.ucdavis.edu

Palliative Excellence in Alzheimer's Care Efforts (PEACE): Implementation and Evaluation of Model Programs to Improve End-of-Life Care for Alzheimer's Patients
University of Chicago Medical Center
Chicago, Ill.
Amount: $449,300
Dates: October 1998 to June 2002
ID#: 035485

Contacts
Greg A. Sachs, MD, Project Director
(773) 702-0102
gsachs@medicine.bsd.uchicago.edu
Patricia Hanrahan, PhD, Project Director
(773) 702-9697
phanrahan@yoda.bsd.uchicago.edu

PalCare: Comprehensive Palliative Care Program for People with AIDS
Louisiana State University Health Sciences Center
New Orleans, La.
Amount: $446,334
Dates: October 1998 to September 2003
ID#: 035482

Contacts
Harlee Kutzen, MN, ACRN, Project Director
(504) 568-7041
hkutzen@aol.com
James Zachary, MD, Project Director
(504) 903-7049
jzacha@lsuhsc.edu
Program to Provide Comprehensive End-of-Life Care to People with Serious Mental Illness
Commonwealth of Massachusetts Department of Mental Health, Metro Suburban Area
Medfield, Mass.
   Amount: $449,305
   Dates: October 1998 to March 2004
   ID#: 035497

Contact
Mary Ellen Foti, MD, Project Director
(508) 616-3503
Maryellen.foti@dmh.state.ma.us

FOOTPRINTS™: Community-Based Hospice Services for Terminally Ill Children and Their Families
Cardinal Glennon Children's Medical Center
Saint Louis, Mo.
   Amount: $448,436
   Dates: October 1998 to April 2003
   ID#: 035489

Contacts
Mary Ann Collins, MHA, Current Project Director
Mary_Ann_Collins@ssmhccom
Suzanne S. Toce, MD, Former Project Director
tocess@charter.net

When Cure is no Longer Possible: Development of a Culturally Appropriate Palliative Care Network for Rural New Mexico
University of New Mexico Health Sciences Center
Albuquerque, N.M.
   Amount: $449,856
   Dates: October 1998 to March 2002
   ID#: 035487

Contact
Walter B. Forman, MD, Project Director
(505) 277-0903
wbforman@unm.edu
Palliative Care Services for Urban African-Americans: Project to Improve Palliative Services and End-of-Life Care
Medical University of South Carolina
Charleston, S.C.
Amount: $163,474
Dates: October 1998 to June 2000
ID#: 035475
Contact
Jerome Kurent, MD, Project Director
(803) 792-0263
kurentje@musc.edu

Pediatric Palliative Care Project: Improving Access to and Quality of End-of-Life Services for Children and Their Families
Children's Hospital Foundation
Seattle, Wash.
Amount: $449,948
Dates: October 1998 to September 2001
ID#: 035495
Contacts
Ross Hays, MD, Project Director
(206) 526-2000
rhays@chmc.org
Russ Geyer, MD, Project Director
(206) 526-2106
rgeyer@chmc.org

Projects Focused on Patients with Specific Diseases and Conditions
PhoenixCare: Palliative Care Program for People in Managed Care
Hospice of the Valley
Phoenix, Ariz.
Amount: $450,000
Dates: January 1999 to December 2001
ID#: 035492
Contact
Carol Lockhart, RN, PhD, Project Director
(480) 345-9445
carol@lockhartassociates.com

Renal Palliative Care Initiative: Palliative Care Program to Improve End-of-Life Care for People with End-Stage Renal Disease and Their Families
Baystate Medical Center
Springfield, Mass.
Amount: $450,000
Dates: October 1998 to June 2002
ID#: 035474

Contact
Lewis M. Cohen, MD, Project Director
(413) 794-3376
lewis.cohen@bhs.org

Randomized Trial to Determine the Benefits of Earlier Hospice Care for Patients with Incurable Diseases
University of Michigan Comprehensive Cancer Center
Ann Arbor, Mich.
Amount: $450,000
Dates: October 1998 to June 2002
ID#: 035478

Contacts
John Finn, MD, Project Director
(313) 578-5000
jfinn@hom.org
Kenneth Pienta, MD, Project Director
(734) 637-3421
kpienta@umich.edu

Project ENABLE: Integrated Palliative Care Program for Cancer Patients
Dartmouth-Hitchcock Medical Center Norris Cotton Cancer Center
Hanover, N.H.
Amount: $449,960
Dates: October 1998 to December 2001
ID#: 035480

Contact
Marie Bakitas, ARNP, PhD, Project Director
Marie.Bakitas@hitchcock.org

Project Safe Conduct: Collaborative Interagency Program to Improve End-of-Life Care for Cancer Patients and Their Families
Case Western Reserve University
Cleveland, Ohio
Amount: $450,000
Dates: October 1998 to December 2003
ID#: 035483

Contact
James K.V. Willson, MD, Former Project Director
(216) 844-8562
jkw@po.cwru.edu

Projects Focused on Challenging Clinical Settings

Balm of Gilead: Comprehensive Palliative Care Services for Medically Underserved Persons in an Urban Setting
Cooper Green Hospital Foundation
Birmingham, Ala.
Amount: $446,933
Dates: October 1998 to September 2001
ID#: 35476

Contact
F. Amos Bailey, MD, Project Director
(205) 933-8101, ext. 5355
amos.bailey@med.va.gov

Enhancing Communication: Development of a Flexible Palliative Care Program to Improve Quality of End-of-Life Care
Henry Ford Health System
Detroit, Mich.
Amount: $442,722
Dates: October 1998 to September 2002
ID#: 035484
Contact
Leslie J. Bricker, MD, Project Director
(313) 916-1859
lbricke1@hfhs.org

Integrated Case Management to Improve End-of-Life Care for Elderly Patients in Managed Care
Mount Sinai School of Medicine of New York University
New York, N.Y.
Amount: $449,658
Dates: October 1998 to August 2002
ID#: 035488

Contacts
Diane Eve Meier, MD, Project Director
(212) 241-1446
diane.meier@mssm.edu
William Thar, MD, MPH, Former Project Director
(201) 512-7067
tharb@franklinhealth.com

Advanced Illness Management Program (AIM): Comprehensive Home-Based Options for Informed Consent about End-of-Life Services for Capitated Medicare Enrollees
Sutter Visiting Nurse Association and Hospice
Forestville, Calif.
Amount: $449,994
Dates: October 1998 to September 2005
ID#: 035494

Contact
Brad Stuart, MD, Project Director
(510) 450-8533
StuartB@sutterhealth.org

Comprehensive Care Team Approach to Providing Palliative Care at the Beginning of End of Life
University of California, San Francisco, School of Medicine
San Francisco, Calif.
Amount: $450,000
Dates: October 1998 to June 2002
ID#: 035486

Contact
Michael W. Rabow, MD, Project Director
(415) 502-6614
mrabow@medicine.ucsf.edu

Palliative Care Program for People Dying in Nursing Homes
University of Pennsylvania School of Nursing
— Amount: $450,000
   Dates: November 1998 to February 2002
   ID#: 035491

Contact
Neville Strumpf, PhD, RN, Project Director
(215) 898-8283
strumpf@nursing.upenn.edu

GRACE: Providing Quality End-of-Life Care to Inmates
Volunteers of America
Alexandria, Va.
   Amount: $251,696
   Dates: March 2000 to March 2002
   ID#: 038866
   Amount: $198,304
   Dates: December 1998 to February 2000
   ID#: 035481

Contact
Margaret Ratcliff, MSW, Project Director
(703) 341-5039
mratcliff@voa.org

Promoting Palliative Care Excellence in Intensive Care Sites
Merging a Palliative Care Program with a Medical Intensive Care Unit
General Hospital Corporation-Massachusetts General Hospital
Boston, Mass.
Amount: $375,000
Dates: March 2003 to June 2006
ID#: 047997

Contacts
J. Andrew Billings, MD, Project Director
(617) 724-9197
Jbillings@partners.org
Adele Keeley, RN, Project Director
(617) 726-2594
akeeley@partners.org

Implementing Palliative Care in an Inner-City Trauma/Surgical Intensive Care Unit
Foundation of the University of Medicine and Dentistry of New Jersey Medical School Newark, N.J.
Amount: $374,770
Dates: March 2003 to September 2006
ID#: 047998

Contacts
Anne C. Mosenthal, MD, Project Director
(973) 972-6398
mosentac@umdnj.edu
Patricia Murphy, PhD, A.P.N., Project Director
(973) 972-7251
murphypa@umdnj.edu

Implementing Palliative Care in Three Community Hospital Intensive Care Units
Lehigh Valley Hospital and Health Network Allentown, Pa.
Amount: $375,000
Dates: March 2003 to October 2006
ID#: 047999

Contacts
Daniel Ray, MD, Project Director
(610) 439-8856
Introducing Interdisciplinary Palliative Care Services in Seven Intensive Care Units
University of Washington School of Medicine
Seattle, Wash.
Amount: $371,150
Dates: March 2003 to February 2007
ID#: 047996
Contacts
J. Randall Curtis, MD, MPH, Project Director
(206) 731-2106
jrc@u.washington.edu
Patsy D. Treece, RN, Project Director
(206) 731-2424
ptreece@washington.edu

Special Opportunities Fund Grants

Talking Circles: Palliative Care Networks for Native Americans
All Indian Pueblo Council, Inc.
Albuquerque, N.M.
Amount: $157,050
Dates: November 2000 to October 2001
ID#: 040480
Contact
Amadeo Shije
(505) 881-1992
amadeo@aipcinc.com

National Advanced Illness Coordinated Care Project
Research Foundation of State University of New York
Albany, N.Y.
Amount: $100,000
Dates: November 2000 to June 2003
ID#: 040479

**Contact**
Daniel R. Tobin, MD, Project Director
(518) 433-4601
tobindr@aol.com

**Supportive Care Coalition: Building on Organizational and Community Strengths in Providing End-of-Life Care**
Providence Health Systems, Oregon Region
Portland, Ore.
Amount: $195,000
Dates: August 2001 to December 2003
ID#: 043055

**Contacts**
Sylvia McSkimming, PhD, RN, Project Director
(503) 255-4027
mcskimm@comcast.net
Karin Dufault, SP, RN, PhD, Executive Director of Providence Health Systems, Oregon Region
(503) 215-5053
karin.dufault@providence.org

**Measuring the Quality of End-of-Life Care in the Intensive Care Unit**
Rhode Island Hospital
Providence, R.I.
Amount: $230,700
Dates: November 2002 to March 2005
ID#: 046819

**Contact**
Mitchell M. Levy, MD, Project Director
(401) 444-5518
Mitchell_Levy@brown.edu

**Children's Hospice and Palliative Care Project**
National Hospice and Palliative Care Organization
Alexandria, Va.
Amount: $49,975
Establishment of a National Educational Resource Center on Palliative Care and HIV/AIDS
University of Washington School of Medicine
Seattle, Wash.
Amount: $149,450
Dates: August 2001 to October 2003
ID#: 043063
Contact
Anthony L. Back, MD, Project Director
(206) 277-1044
tonyback@u.washington.edu

Survey of Critical Care Fellows on Palliative and End-of-Life Care Training
Dartmouth-Hitchcock Medical Center
Hanover, N.H.
Amount: $85,110
Dates: January 2003 to December 2005
ID#: 042705
Contact
Thomas J. Prendergast, MD
(603) 650-5262
thomas.j.prendergast@hitchcock.org

Peer Mentoring: Improving End-of-Life Planning for End-Stage Renal Disease Patients and Their Families
National Kidney Foundation of Michigan
Ann Arbor, Mich.
Amount: $57,390
Dates: February 2002 to January 2003
ID#: 043875
Contact
Erica E. Perry, MSW, Project Director
(734) 971-2800
eperry@umich.edu

Developing a Research and Education Agenda to Improve End-of-Life Care in ICUs
University of Washington
Seattle, Wash.
Amount: $113,466
Dates: November 1998 to October 1999
ID#: 035083

Contacts
Gordon D. Rubenfeld, MD, MSc, Project Director
(206) 731-3356
nodrog@u.washington.edu
J. Randall Curtis, MD, MPH, Project Director
(206) 731-2106
jrc@u.washington.edu
APPENDIX 3

Peer Professional Workgroup Chairs

Amyotrophic Lateral Sclerosis Workgroup
Hiroshi Mitsumoto, MD
Eleanor & Lou Gehrig MDA/ALS Center
College of Physicians & Surgeons
Columbia University Neurologic Institute
New York, N.Y.

Children's International Project on Palliative/Hospices Services Workgroup
Marcia Levetown, MD
Pain and Palliative Care Education Consultant
Houston, Texas

Cost Accounting Workgroup
Stephen Seninger, PhD
Director of Economic Analysis
Bureau of Business and Economic Research
Professor, University of Montana
Missoula, Mont.

Critical Care Workgroup
Mitchell Levy, MD
Professor, Brown University
Director, Medical Intensive Care Unit
Rhode Island Hospital
Providence, R.I.

End-Stage Renal Disease Workgroup
Alvin H. (Woody) Moss, MD
Professor of Medicine & Director
Center for Health Ethics and Law
Robert C. Byrd Health Sciences Center
West Virginia University
Morgantown, W.Va.

HIV/AIDS Palliative Care Workgroup
Carla S. Alexander, MD
Clinical Assistant Professor of Medicine
Institute of Human Virology
University of Maryland School of Medicine
Baltimore, Md.

Anthony L. Back, MD
Associate Professor
University of Washington
VA Puget Sound Health Care System
Seattle, Wash.

Huntington's Disease Workgroup
Richard Dubinsky, MD
Associate Professor of Neurology
University of Kansas Medical Center
Kansas City, Kan.

Surgeons Palliative Care Workgroup
Geoffrey P. Dunn, MD
Medical Director
Great Lakes Hospice
Erie, Pa.

Robert A. Milch, MD
Medical Director
Center for Hospice and Palliative Care
Cheektowaga, N.Y.
APPENDIX 4

Evaluation Mentors

(Current as of the time of the grant; provided by the grantees or organizations; not verified by RWJF.)

Melanie Pratt Merriman, PhD, MBA, Coordinator
Touchstone Consulting
North Bay Village, Fla.

J. Randall Curtis, MD
Assistant Professor of Medicine
Harborview Medical Center
Seattle, Wash.

Pam Kovacs, PhD, MSW
Assistant Professor
School of Social Work
Virginia Commonwealth University
Richmond, Va.

Steven Miles, MD
Associate Professor of Medicine
University of Minnesota Center for Bioethics
Minneapolis, Minn.

Kay Norris, PhD
Research Manager
Missoula Demonstration Project
University of Montana
Missoula, Mont.

Karen Steinhauser, PhD
Assistant Research Professor, Health Scientist
Duke University Medical Center and Veteran's Administration Medical Center
Durham, N.C.

Joan Teno, MD
Associate Professor of Community Health
Department of Community Health
Brown University
Providence, R.I.

Beth Virnig, PhD
Assistant Professor
School of Public Health
University of Minnesota
Minneapolis, Minn.

Diana Wilkie, PhD, RN
Professor and Harriet Werley Endowed Chair for Nursing Research
Department of Medical-Surgical Nursing
College of Nursing
University of Illinois at Chicago
Chicago, Ill.
APPENDIX 5

Ten Essential Ingredients for Building Successful Palliative Care Programs

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

Over the course of the program, the national program office and demonstration project staff members distilled 10 essential components of palliative care programs:

1. **A well-defined vision** that advances the institution's mission and encompasses a comprehensive definition of palliative care.

2. **A well-planned implementation strategy** that is manageable in scope and consistent with available human and financial resources.

3. **Unwavering support from clinical and administrative leaders** willing to champion the program and help secure operational resources.

4. **Ongoing efforts to bridge the differences between palliative and acute care clinical cultures** that entail learning on both sides and integrate experienced staff with diverse expertise, including psychosocial and spiritual care.

5. **A focus on making ”the right way the easy way”** by responding to workday needs of time-pressed clinicians and management and redesigning operations to embed and trigger palliative practices in daily routines.

6. **Ongoing education, support and attention to team building for clinicians and system personnel** to ease adoption of innovation and strengthen clinical interventions.

7. **An assurance that palliative care teams have the authority** to carry out their clinical recommendations and interventions for patient care and "safe havens" for the discussion of problems and ideas.

8. **Attention to diverse ethnic and religious cultures of individual patients and families** through sensitivity to the uniqueness of individuals and their preferences and careful selection of language to convey program elements.

9. **Targeted data collection** focusing on increased access to palliative care, improved quality of care, resource utilization and cost and patient/family/clinician satisfaction.

10. **A communications strategy for succinctly presenting relevant data to stakeholders.**
BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

National Program Office Bibliography

Books


Book Chapters


Articles


**National Program Office Reports**


**Workgroup Reports**

A Typical Peer-Professional Workgroup Life Cycle

Roles and Responsibilities

Charter Template

The Peer-Professional Workgroup Guidelines for Final Product Recommendations to the Field

Amyotrophic Lateral Sclerosis Peer Workgroup


Children’s International Project on Palliative/Hospice Services Workgroup


Compendium of Pediatric Palliative Care, Children’s International Project on Palliative/Hospice Services Workgroup. Alexandria, VA: National Hospice and Palliative Care Organization, 2000. Can be ordered from the National Hospice and Palliative Care Organization at its website.

Cost Accounting Workgroup


Critical Care Workgroup


Seven End-of-Life Care Domains: Associated Quality Indicators and Related Clinician and Organizational Interventions Behaviors

— Domain 1: Patient and Family Centered Decision Making
— Domain 2: Communication with the Team & Patients/Families
— Domain 3: Continuity of Care
— Domain 4: Emotional & Practical Support for Patients/Families
— Domain 5: Symptom Management & Comfort Care
— Domain 6: Spiritual Support for Patients/Families
— Domain 7: Emotional & Organizational Support for ICU Clinicians
— Worksheets.

End-Stage Renal Disease Workgroup

- *End-Stage Renal Disease Workgroup Final Report: Recommendations to the Field.*
- Moss A and the Promoting Excellence in End-of-Life Care ESRD Workgroup. *Completing the Continuum of Nephrology Care: Recommendations to the Field.* Also available on CD-ROM.

HIV / AIDS Palliative Care Workgroup

- *Recommendations to the Field-HIV Care: An Agenda for Change.*

Huntington's Disease Workgroup

- *Huntington's Disease Recommendations to the Field.*

Surgeons Palliative Care Workgroup

- *Recommendations to the Field Summary. Office of Promoting Excellence in End-of-Life Care: Surgeons' Palliative Care Workgroup Report to the Field.*
- *Journal of American College of Surgeons* (JACS) has featured a 20-plus article series on palliative care in surgery, the editor of which was workgroup co-chair Geoffrey Dunn. JACS has compiled these articles into a publication titled *Palliative Care By The Surgeon: A Compendium.* The articles are:


— Dunn G. "Patient Assessment in Palliative Care: How to See the 'Big Picture' and What to Do When 'There is No More We Can Do.'" 193(5): 565–573, 2001.


— Mosenthal AC and Murphy PA. "Trauma Care and Palliative Care: Time to Integrate the Two?" 197(3): 509–516, 2003.


**Audio-Visuals and Computer Software**


**Tools and Survey Instruments**

End-State Renal Disease Workgroup Quality of Life Tools:

- Quality of Life Questionnaire for Dialysis Patients. The surveys were conducted in Washington; Mineola, NY; and Morgantown, WV, August–November 2001.

- McGill Quality of Life Questionnaire

- Addendum to McGill QOL Questionnaire

- Satisfaction with Life Scale (SWLS)

- Patient Satisfaction, Newmann and Pfettscher (Adapted From KDQOL)

- Patient Satisfaction (Adapted from DiMatteo and Hays)


**Grantee Websites**

www.promotingexcellence.org (no longer available). Website for the national program, Promoting Excellence in End-of-Life Care. Provided information about the national program Promoting Excellence in End-of-Life Care demonstration projects, national workgroups and evaluation and technical assistance plan. A section of the website was devoted to tools and resources. Missoula, MT: Promoting Excellence in Care at the Center for Ethics, University of Montana, 1999.

**Presentations and Testimony**

Ira R. Byock, "Improving Care at the End of Life with Complementary Medicine," to the Committee on Government Reform of the Congress of the United States House of Representatives, October 19, 1999, Washington. Written request from committee chair, Representative Dan Burton. Testimony of the hearing available online.

Ira Byock, B Taylor Thompson, Patsy Treece, Adele Keeley, Cathy Fuhrman and Patricia Murphy, "Integrating Palliative Care into the ICU," Mastery Session at the American Association of Critical Care Nurses' National Teaching Institute, May 10, 2005, New Orleans.

**Project Sites Bibliography**

**Articles**


**Reports**


**Tools and Survey Instruments**


*Integrating Palliative and Critical Care—An ICU Intervention to Improve End-of-Life Care.* University of Washington Schools of Medicine and Nursing

*Integrating Palliative and Critical Care.* Newark, NJ: University of Medicine and Dentistry of New Jersey


"Quality of Dying and Death Questionnaire for Family Members," Seattle: Washington University Schools of Medicine and Nursing.


*Structured Family Meetings—Dealing with Conflict.* Boston: Massachusetts General Hospital and Harvard Medical School

*V.A.L.U.E. Pocket Card.* Allentown, PA: Lehigh Valley Hospital and Health Network

*Ventilator Withdrawal Guidelines.* Boston: Massachusetts General Hospital and Harvard Medical School

*Withdrawal of Life-Sustaining Measures Order Form.* Seattle: University of Washington Schools of Medicine and Nursing.

**Audio-Visuals and Computer Software**

Charting Your Course: A Whole Person's Approach to Living with Cancer, an educational seminar on CD-ROM. Lebanon, NH: Dartmouth-Hitchcock Medical Center, Norris Cotton Cancer Center, 2001.


Integrating Palliative and Critical Care: An Educational Video About Improving Palliative Care in the ICU. Seattle: University of Washington. Available online.


November is National Hospice Month, radio ads for five hospice programs in New Mexico on CD-ROM. Albuquerque, NM: University of New Mexico Health Sciences Center, November 2002.


PROJECT LIST

Developing a Research and Education Agenda to Improve End-of-Life Care in ICUs
A December 1998 workshop engages 43 experts
University of Washington (ID# 35083)
Seattle, Wash.

FOOTPRINTS™
Community-based hospice services for terminally ill children and their families
Cardinal Glennon Children's Medical Center (ID# 35489)
Saint Louis, Mo.

Ikayurem Unatai (Helping Hands)
Establishment of a culturally sensitive rural hospice program for Alaska natives
Bristol Bay Area Health Corporation (ID# 35496)
Dillingham, Ala.

Introducing Interdisciplinary Palliative Care Services in Seven ICUs
Harborview Medical Center seeks to improve the quality of end-of-life care
University of Washington School of Medicine (ID# 47995)
Seattle, Wash.

Pathways of Caring
Model program to provide comprehensive palliative care to veterans
Brentwood Biomedical Research Institute Inc., West Los Angeles Veterans Affairs Medical Center ID# 35493)
Los Angeles, Calif.

Peer Professional Workgroup on Amyotrophic Lateral Sclerosis (ALS)
Bringing medical leaders together for idea generation
(funded through the national program office, ID# 37526)

Project Safe Conduct
Collaborative interagency program to improve end-of-life care for cancer patients and their families
Case Western Reserve University (ID# 35483)
Cleveland, Ohio