

CIRCLE OF LIFE AWARD



2000



CIRCLE of LIFE

Celebrating Innovation in End-of-Life Care

Sponsored by the American Hospital Association in conjunction with the American Medical Association,
the American Association of Homes and Services for the Aging, and the National Hospice and Palliative Care Organization.
The Circle of Life Award is supported by a grant from The Robert Wood Johnson Foundation.

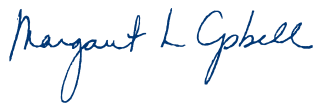
The Circle of Life Awards grew from an observation, quietly made by Christine Cassel, M.D., of New York's Mount Sinai Medical Center: "There are no awards for excellent care given to the dying...the feeling of professional satisfaction is not based on easing death for the hopelessly ill."

The American Hospital Association and the Robert Wood Johnson Foundation wanted that to change and the result was the creation of the Circle of Life Awards: Celebrating Innovation in End-of-Life Care. We sought co-sponsors — the American Medical Association, the National Hospice and Palliative Care Organization, and the American Association of Homes and Services for the Aging — who share our goal of changing and improving the culture of dying in America...to move away from the professional attitudes and culture that equate death with a failure of science. Those honored in the Circle of Life are innovators in serving patients near the end of life and their families.

Some 120 programs shared their stories with us. Nine were selected to be honored this first year for their outstanding innovations and commitment. Three programs will receive the Circle of Life Award. They are: *"Improving Care Through the End of Life,"* Franciscan Health System (Gig Harbor, Washington); *The Hospice of the Florida Suncoast* (Largo, Florida), and the *Louisiana State Penitentiary Hospice* (Angola, Louisiana). Six programs — *Beth Israel* (New York City), the *Butterfly Program* (Galveston, Texas), *Calvary Hospital* (Bronx, New York), *Fairview Health Services* (Minneapolis, Minnesota), the *Harry Horvitz Center at Cleveland Clinic* (Cleveland, Ohio), and the *San Diego Hospice Corporation* (San Diego, California) — will receive honorable mention. All of their stories are in this booklet with the hope that they may provide ideas and inspiration to other health care organizations.

Choosing just three winners and six honorable mentions was difficult for the Circle of Life Awards Committee. Many programs not being honored this year are changing the way death is viewed in their health care organizations and communities in creative and profound ways: the hospice haven within a hospital at Hospice House of Mid-Michigan...the clown corps of the Hospice of Ashtabula County (Ohio)...the *kitchen table* advance care planning at Allina Hospice and Palliative Care (Minnesota)...the comfort care suites at University of California–San Francisco Medical Center...the caregiver bereavement program at Dana Farber (Massachusetts)...the *abider* program at Community Memorial Hospital of Menomonee Falls (Wisconsin)...the primary care orientation of the Massachusetts General Palliative Care Service...are just some of the many impressive efforts making a difference in their communities.

Special thanks to all the programs that applied for the Circle of Life Award in its first year, to the Circle of Life Awards Committee, and particularly to the Robert Wood Johnson Foundation for its funding and support.



Margaret Campbell, R.N.
Chairman
Circle of Life Awards Committee
1999–2000



Dick Davidson
President
American Hospital Association

AWARD WINNER

THE HOSPICE
OF THE FLORIDA SUNCOAST

Largo, Florida





When the staff of Friendship Retirement Residence in central Florida was starting to show the strain of working with an older, sick clientele on top of some tough personal losses, Administrator Jeralyn Altenburg knew where to turn. She asked The Hospice of The Florida Suncoast to send a grief counselor to talk with the staff and offer some additional one-on-one counseling.

Robert Ammon, the principal of Southern Oak Elementary School, had a similar need when a child at the school died suddenly. “They sent a counselor right over,” he says of The Hospice. “She assessed the situation and instituted an action plan. I didn’t have the expertise for the situation and they really took over.”

These are just two examples out of thousands of people’s lives that have been affected by The Hospice of The Florida Suncoast. The 22-year-old institution not only provides end-of-life care for 4,700 people each year, but has become known in the community as the place to go for support when death touches life.

The Hospice is being recognized by the Circle of Life Award in part for its comprehensive approach — it’s the only hospice in Pinellas County because it does so well no other health care organization has needed to step into that role. And it’s a big job — the county’s elders comprise 26 percent of the total population, double the national average. The Largo-based group has 850 employees and an active base of 2,600 trained volunteers who work with the dying, their families, and the community at large.

What also makes the organization worthy of note is that it has taken on responsibility for the emotional well-being of its community.

For instance, The Hospice makes a point of reaching out to parts of the community that could use its bereavement services. Through its *Bridges* and other community programs, thousands of people get grief counseling. This occurs in local businesses affected by death or terminal illness in the workplace or in doctors’ offices, where the *Patients’ Access to Hope* program works with local physicians to provide on-site counseling support at the time a serious illness is diagnosed. The Hospice has found creative ways to reach out to people in pain; for instance, it has contacted trust officers in banks who have spent many years in financial counseling only to lose their client friends. Similarly, police officers, funeral directors, and other people who regularly come in contact with death can get help from The Hospice.

The Hospice’s extensive bank of volunteers is used to support specialized bereavement groups for people in different situations, such as survivors of homicide or suicide, and widows or widowers of working age.

Joan Kindey started volunteering for the hospice bereavement program after using the services herself when her husband Hal died in 1997. He used The Hospice for seven months while sick with prostate cancer. “They were so incredibly good to me,” Kindey recalls. “I tried to be a superwoman for awhile and do everything, but then I realized I needed to get out of the house. A wonderful man came in once a week. He and Hal would talk about boats or sports.”

After Hal died, it took Joan several months before she was ready to seek support from a bereavement group, but she ultimately did. “They helped me get myself together and prepare for the future. Then, I felt I had to pay back and took the volunteer training.”

One of the strengths of the program is its size, but we didn't want to lose touch with the community. We want to be seen as accessible.



INNOVATION HIGHLIGHTS

CREATIVE COMMUNITY PROGRAMS

QUALITY OF LIFE FUND

INTERGENERATIONAL VOLUNTEER PROGRAM

LIFETIME LEGACIES PROGRAM — HIGH SCHOOL STUDENTS VIDEO TAPE PATIENTS' STORIES AND MEMORIES

BEREAVEMENT CHILDREN'S CAMP AND FAMILY-TO-FAMILY RETREATS

PALLIATIVE CARE AND HOSPICE REFERENCE TOOLS

HOSPICE SOFTWARE TOOL

As a retired psychology professor who once taught courses in group counseling, Kindey knows a well-designed support group when she sees it, and has been impressed with the way meetings are run and volunteers are monitored. They are trained to give support but not counseling, and to maintain contact with people who need extra attention.

“One thing they helped us realize as survivors and volunteers is that there is no set pattern for the grief process,” Kindey says. “‘Normal’ is a setting on the washing machine. Everything else is helping people understand the feelings they have are normal for them.”

Another innovative community-based program involves teens. High school students are recruited to work with dying patients. One highlight of the *Intergenerational Teen Volunteer Program* has had students interviewing and taping terminally ill patients to provide a lasting legacy to their families. Stewart Schaffer's son Eric participated, and the experience had a lasting impact on him. “Your organization and program have allowed him to learn about the world from real people with real problems,” Schaffer wrote in a testimonial to The Hospice. “He also was able to bond with some of the patients and provide them with a special feeling of self-worth that they may not have experienced otherwise.”

The Hospice's program for the dying has come up with some innovations as well. For instance, the staff is given access to a special “quality of life” fund that they can dip into if a patient needs something special.

The Hospice has also designed a set of palliative care and hospice reference tools, which are “cheat sheets” with reminders for staff about symptom and pain management, complementary therapies, enteral nutrition products, and regulatory resources.

Because it is a large organization, The Hospice set up service centers in four different parts of the county. This way support group meetings, volunteer training, and community education for physicians and nursing home employees can take place in the local community, explains Mike Bell, vice president of development and community relations. “One of the strengths of the program is its size, but we didn't want to lose touch with the community,” Bell explains. “We want to be seen as accessible.”

Hospice care is overseen by interdisciplinary teams, which includes the patient and family along with staff and volunteers.

About half The Hospice's patients are seen in their own homes. The organization also offers two other types of residential care options: a 67-bed residence with 24-hour care but total freedom for patients and their families to visit; and villas for terminally ill people who have limited financial resources but are still capable of living independently with supportive care.

The Hospice of the Florida Suncoast has served more than 50,000 people since its establishment in 1977, and has developed its own management software that is sold to 28 other hospices. •

END-OF-LIFE CARE INITIATIVE
FAIRVIEW HEALTH SERVICES

Minneapolis, Minnesota

When a patient is dying, family and friends come to the bedside amid a swirl of emotion — pleasant memories of happier times, regrets about an unkind word once uttered, realization of the special qualities of the person they’re about to lose. Sometimes those thoughts are hard to share with others, but Fairview Health Services in Minnesota has a way for those visitors to vent their feelings — through a grief journal, a notebook left by the bedside that anyone, including medical staff, can use to record their thoughts. The book is then given to the family to help them through the bereavement process.

The journal is just one small way that Fairview’s end-of-life team improves the final days of life for patients and their families. On a larger scale, Fairview’s efforts are noteworthy because they are spread across a broad continuum — the system includes seven hospitals, three physician networks, 75 clinics, three nursing homes, 14 senior residences, and 22 physical therapy sites, along with 20 retail pharmacies, rehabilitation services, home care, and hospice.

Fairview was recognized because of its success in improving end-of-life care in pilot projects and then replicating them in other settings. That effort is only a couple of years old, and has already yielded success in several ways.

For instance, the team distributed throughout the entire system a laminated card that offers several different ways for patients to rate their pain on a one-to-ten scale, or with colors or facial expressions that correlate to a number. This allows more precise symptom and pain control, and helps health professionals



follow the success of their treatments. It was a low-cost innovation paid for by the Fairview auxiliary.

In addition, the system has adopted a “surrogate decision maker” policy in all settings. This is accomplished by asking every patient upon admission who they would like to make decisions for them if they are incapacitated. The policy reduces confusion in a crisis when it may be unclear which family member best represents the patient’s wishes. In addition, in a pilot program at a rural site where Fairview physicians care for patients almost exclusively, an advanced directive and care plan was developed for use whenever a patient has a history and physical. The original pink form stays with the patient from setting to setting, while a copy is put in the chart in each place where care was previously delivered.

To advance pain and symptom control throughout the system, a set of palliative care standing orders was developed. Physicians needed guidance in the fast-evolving field of pain management; the orders also address complementary therapy, herbal medications, spiritual health consultation, and behavioral medicine intervention for depression.

Pain control has been a priority of the end-of-life team, which helped spearhead a pilot program on an oncology unit within Fairview Southdale Hospital that reduced the average number of hours to control pain from 54 to 16. This was accomplished in five months by allowing nurses to continue administering medication until the patient’s goal for pain relief is met.

Grant funding will help the system establish a new bereavement services program in which trained volunteers contact the families of every patient who dies within the system. This program should be cost-effective, since the system pays only for a volunteer coordinator. This particular innovation has a goal to identify complex grief and help families in any way possible. Many of these innovations could be accomplished by other health care organizations, asserts Mark Leenay, M.D., director of palliative medicine for the system. “We made the case (to management) that if we do this right and do it well, we’ll improve the quality of care without increased cost,” Leenay says.



INNOVATION HIGHLIGHTS

**SURROGATE DECISION MAKER
IDENTIFICATION**

**TRANSITIONS AND LIFE CHOICES
PROGRAM**

GRIEF JOURNAL

PALLIATIVE CARE KITS FOR ALL UNITS

CALVARY HOSPITAL

Bronx, New York

The palliative care movement has gained a lot of steam in the last few years. But there's one institution that has been specializing in such care for the last century.

Calvary Hospital in the Bronx, New York, is a 200-bed acute care facility for adults suffering from advanced cancer, and is unique in the nation for its size, longevity, and commitment to improving the end of life for its patients.

"Palliative care went from a function that no one was interested in, to one that is academically and clinically interesting to everyone," says CEO Frank Calamari. "We were there before anyone wanted to do this. We're proud of that."

The cardinal rule at Calvary is "non-abandonment," meaning that there is never a time when "nothing more" can be done. The staff works as a team to be alert to changes in the patient's physical and psychological condition, and aware of any new therapies that could provide comfort.

The special care starts upon admission, when each patient is given a rose. Each of the institution's 200 rooms is private and equipped with a color television, VCR, and private telephone. Each floor has special suites outfitted with a sofa bed, bathroom, and kitchenette to accommodate family members when patients are critical. Visiting hours are 24 hours a day, and the family pet can come along in certain areas. Transportation assistance is provided twice a week to needy family members to visit their loved ones. "The disease, when it's in a patient, is also in a family," explains Calamari.



The hospital's 771 full-time and part-time employees have each gone through a two-day orientation program during their first week of employment. The staff is augmented by 210 volunteers, each of whom serves an average of 190 hours each year. Care is provided to 2,400 inpatients yearly.

Each patient is assigned a physician, who visits daily to oversee the care plan. The care team also includes a multi-lingual, multi-denominational pastoral care staff, with a chaplain available 24 hours a day. Bereavement support and counseling is available to family members and friends, with a special component for children.

The hospital hosts more than 400 medical students and physicians in training throughout the academic year from area medical schools. "However, we are always mindful to emphasize the priority of life and the privacy of our patients. We feel that by reaching students early in their training, the Calvary experience will influence how they treat patients throughout their careers," says James Cimino, M.D., Director of the Patient Care Institute. The Calvary

Palliative Care Institute, which sponsors research and education, also sponsors numerous lectures and conferences on palliative care.

Advice from Calamari to new programs: "You have to develop a culture. You have to gather physicians that will be courageous enough to use pain control medications in their appropriate designations and quantities as well as a nursing staff that is mission driven and dedicated to delivering the best quality of life care to both patients and their families."

Calvary is taking advantage of its expertise to establish a 25-bed "hospital within a hospital" palliative care program at Lutheran General Hospital across town in Brooklyn. Calvary hopes to set up more such satellites throughout the New York area.

Calamari sees enlightened care of the dying becoming a discipline just like any other in medicine, with its own place in each American hospital. "It's a part of life."



INNOVATION HIGHLIGHTS

TOTALLY RESTRAINT-FREE
ENVIRONMENT

APPROACH AND COMMITMENT TO
NON-ABANDONMENT

BEREAVEMENT PROGRAM FOR
CHILDREN/BEREAVEMENT TRAINING
FOR TEACHERS

HARRY R. HORVITZ CENTER FOR PALLIATIVE MEDICINE CLEVELAND CLINIC

Cleveland, Ohio

It's taken more than a decade, but the Cleveland Clinic's Harry R. Horvitz Center for Palliative Medicine has grown from a good idea being carried out by a physician, nurse, and a part-time social worker, to a large, self-sustaining program that serves hundreds of patients each year. Many are cared for in the center's 23-bed inpatient palliative medicine unit, the first in an acute care setting.

The center's leaders describe their work as "palliative medicine," focusing on pain and symptom control with curative care as well as end-of-life care. "We are doing very intensive medical care," explains Susan LeGrand, M.D., an oncologist and pain specialist.

Still, the center works closely with the hospice of Cleveland Clinic, which is part of the Palliative Care Program. Each patient is assigned a nurse case manager, who coordinates care whether inpatient, at home, or in the hospice. "We have the whole range of services a person might need in their trajectory of disease," LeGrand explains.

One major accomplishment has been integrating palliative medicine into the full acute care continuum of the renowned multispecialty clinic. That happened in part because the program was established by physicians and respects referring physician preferences.

A key part is the family conference, a formal meeting held at the beginning of care that involves the family, patient, physicians, and case manager. This gives the patient a chance to tell the family and the medical team how much intervention or therapy is wanted — sometimes much less than expected. If the prognosis



gives a patient a short time, the palliative medicine specialists emphasize that the patient has a choice about how to spend that time: "Do you want that last chemotherapy if you have days or weeks, or do you want to go visit your grandchildren?" LeGrand explains.

The program also feeds patient's emotional needs. For instance, a good night's sleep can make the difference in how patients feel, so no blood tests or other laboratory work are drawn on the inpatient unit before 9 a.m. The overhead paging system for the hospital is turned off, and beepers are always kept in vibration mode. Patients have access to music and pet therapy, as well as some alternative treatments. A keyboard-toting music therapist visits three days a week. She helps patients rate their mood and pain, and together they choose songs the therapist might play or they might sing together.

Educating health professionals is another important part of the Cleveland Clinic program. Fellows, residents, medical students, and allied health professionals spend time in the palliative

care unit. The Roxane Scholars program allows outside physicians, nurses, and pharmacists one- or two-week visits.

The Horvitz Center and hospice employ 60 people, including nurses, social workers, chaplains, and nursing assistants, and have 86 trained volunteers.

Many aspects of the Cleveland Clinic palliative care program could be replicated, LeGrand says. "The key is the commitment of the facility and the physicians to better care at the end of life for people with serious illness." She recommends starting slowly — the Horvitz Center started as a consulting service to Cleveland Clinic doctors. "Where we are now is something we grew into over 11 years."



INNOVATION HIGHLIGHTS

INPATIENT PALLIATIVE CARE UNIT

PHYSICIAN-DRIVEN MODEL

VOLUNTEER/FAMILY ADVISORY BOARD

COMPLEMENTARY AND ALTERNATIVE THERAPIES

AWARD WINNER

LOUISIANA STATE PENITENTIARY
HOSPICE PROGRAM

Angola, Louisiana





The maximum security prison in Angola, Louisiana, is known as “the graveyard” — few of its inmates are expected to ever leave. It’s estimated that 85 percent of them will die while incarcerated, and that’s traditionally meant a lonely death in the prison hospital.

But a glimmer of humanity is now shining into the grim interiors of Louisiana State Penitentiary, thanks to warden Burl Cain and a fortuitous meeting with representatives of Louisiana hospice organizations a couple of years ago. The prison was hosting a one-day workshop on AIDS, and among the attendees were a social worker and nurse from a hospice in New Orleans. Cain got to talking with the pair about their work easing the process of dying for patients at a university hospital.

“The warden said, ‘Well, we’ve got a lot of people up here dying,’” relates R. Dwayne McFatter, the prison’s assistant warden for treatment. “We need hospice too. Can you help us start one?”

After a year of efforts to cobble together an end-of-life program at the prison while spending no extra money, Louisiana State Penitentiary now boasts an innovative hospice program that’s become a model for other prisons in Louisiana and across the nation. Inmates dying in the prison hospital can now spend more time with their families, be comforted by specially trained fellow inmate volunteers, and have more focused pain management in a setting that is especially wary of the use of drugs.

All this was accomplished despite the doubts of skeptics, some of whom felt a prison hospice is inappropriate because “inmates don’t deserve to die comfortably and with dignity when their victims didn’t,” prison officials explained in their application for the Circle of Life Award. “This hurdle will be an ongoing struggle. Only education will help society separate the men from their crimes.”

Security staff members were particularly concerned they might lose control of inmates because of increased traffic in and out of the prison hospital. In particular, they worried that it would be more difficult to keep inmates who disliked one another apart — if one enemy was visiting a dying prisoner at the same time as an inmate he wanted to harm.

To allay those fears, organizers of the hospice made sure they included security staff in the development of the concept. Then, as they recruited volunteers from among the inmate population, security officials were able to review the list of names and cross off anyone they thought might make trouble.

Because of security concerns, prison officials nixed the hospice representatives’ original idea that they bring in outside volunteers to tend to the sick inmates. Instead, McFatter says, he started contacting inmates who were active with a number of clubs and organizations within the prison — veterans, Toastmasters, and religious groups, for instance. “I got together with some inmates I’d known for 15 or 20 years,” McFatter recalls. “I explained what it was we’d be asking them to do. I said, ‘You know the inmates better than any of us. Go into the population and find me 40 people who will be doing this for the right reason.’” The resulting list of inmates was screened by McFatter, Security, a nurse, a Classification Officer, and a social worker. The 20 who were chosen went through a 40-hour initial training course.

The program got started with the trained volunteers and one of the hospital’s registered nurses, who became the full-time Hospice Case Manager and Inmate Volunteer Coordinator. The inmate clubs contribute to the hospice some of the

The patients in hospice get regular visits from inmate volunteers, who help them eat, and talk or read to them. Maybe they just hold their hand, just to have somebody there.



INNOVATION HIGHLIGHTS

INMATE VOLUNTEER PROGRAM

DEPTH AND BREADTH OF THE VOLUNTEER TRAINING PROGRAM

IMPACT OF PROGRAM ON RESTORING RESPECT AND DIGNITY TO BOTH PATIENTS AND VOLUNTEERS

MULTI-DISCIPLINARY TEAM WORK, INCLUDING SECURITY

SUPPORT FROM PRISON CLUBS

RELIANCE ON PATIENT'S DEFINITION OF FAMILY

money they raise by selling food such as hot dogs and pizza in the visitors' room. They've also designed a coloring book for children that explains the hospice concept, and sell it for \$2 per copy.

Some of those treats also go to the hospice patients, who might have their first hot dog or hamburger in years through the program. "I had a hospice patient who swore his bowl of ice cream three times a week was keeping him alive," McFatter says.

Potential hospice patients are identified when it's estimated they have about six months to live. They can stay in their housing area as long as they're physically able, and then they are transferred to the prison hospital and a hospice bed.

Only about four of the 36 inmates referred to Hospice have declined to participate. Most accept it willingly, having crossed a psychological barrier. "Some of them want to die peacefully without any pain," McFatter says.

The program served 17 inmates in 1998. The patients in hospice get regular visits from inmate volunteers, who help them eat, and talk or read to them. "Maybe they just hold their hand, just to have somebody there," McFatter says. The volunteers also assist medical staff with moving the patients in and out of bed.

The volunteers benefit from the program as well, McFatter says, because it gives them an unusual opportunity in the macho environment of a maximum security prison to connect with another person. "They tell me it gives them a feeling of self-worth, that they're able to do something for somebody else. Chances are, in years to come, they may be right where their patient is now and they want somebody there with them. Prison is a pretty lonely place."

Patients can choose to see family members, whether they are blood relatives or inmates they've lived with for the past 30 years. Hospice patients get expanded visiting hours. During the last 24 to 36 hours of life, when a doctor or nurse calls a vigil, a volunteer stays with the patient at all times.

One of the most impressive things about the Angola program is that it's been done with no extra budget. And yet, the prison has maintained the hospice program along with offering bereavement support to family members for a year after the death of an inmate. University Hospital Community Hospice in New Orleans helps mentor and educate the staff and volunteers.

Angola officials are helping to export their successful model to two other prisons in Louisiana, and McFatter says he gets regular phone calls from around the country seeking more information about how to start a prison hospice.

"This is the largest maximum security prison in the country," McFatter says. "If we can do it here, anybody can do it." •

DEPARTMENT OF PAIN MEDICINE AND PALLIATIVE CARE
BETH ISRAEL MEDICAL CENTER

New York, New York

Most of us can imagine the discomforts of fighting a serious illness; we've heard about the debilitating nausea that accompanies chemotherapy and the crushing pain of a tumor encroaching on a vital organ. These experiences can infiltrate a patient's entire life in ways that are easy to overlook.

Not so at Beth Israel Medical Center, where pain management and palliative care have become a top priority with the establishment of a Department of Pain Medicine and Palliative Care. In just two years since its founding, the department has grown into a leader of innovation in end-of-life care in the academic medical center setting.

The Beth Israel program is unique because it doesn't restrict itself to patients who are near the end of life, but includes the chronically ill and others who need relief from painful and uncomfortable symptoms of disease.

"We are able to accept patients at any point in the disease course based only on patient need, explains Russell Portenoy, M.D., chairman of the Department of Pain Medicine and Palliative Care. We create a case management model that follows patients along the trajectory of disease."

If and when hospice care is appropriate, the patients can move along that continuum of care directly into the Jacob Perlow Hospice, which falls under the department's purview.

Because patients who need symptom control are identified early on, not only are they more comfortable during treatment for a serious illness, but they also can be referred into hospice care earlier when it becomes clear curative measures are no longer appropriate. Even though hospice programs are designed to see a



person through the last six months of life, the average hospice patient is seen for less than two months.

Among the innovations in the department is a specialized program to address the intense fatigue that often accompanies serious and chronic illness; the program is staffed by two physicians, two advanced practice nurses, a psychologist, and others. Similarly, sexual dysfunction is common in the ill. The Beth Israel program doesn't simply accept this as part of the disease, but has established a *Sexual Health and Rehabilitation Program* in concert with departments of urology, ob/gyn, and the cancer center.

The department has 120 staff and 170 volunteers, and includes a 14-bed inpatient unit. An innovative palliative care drop-in unit allows home care patients to come in for a consultation with a palliative care specialist.

The program uses pain and palliative care specialists to follow patients, but won't take over responsibility for a patient from the referring doctors unless it is requested. The department's expertise in pain management is often welcomed by primary care physicians.

Getting a palliative care program going within a large teaching hospital requires involvement of the administration from the beginning, Portenoy says. "The clinical leadership has to sit down with the senior management from day one and create a business plan that is realistic, but also involves some investment in the future."

A pain and palliative care department can bring value to an institution that may seem intangible, Portenoy says, but ultimately pays off in terms of community support, new philanthropy and an enhanced image. "There's also reason to believe an institution could save money by getting patients out of the hospital faster," he says.

The Beth Israel department's education and research programs are working to document such benefits. Its Institute for Education and Research for Pain and Palliative Care has about 26 staff members, who are conducting clinical trials and carrying out an extensive education program for other health care professionals.



INNOVATION HIGHLIGHTS

PALLIATIVE CARE FOR ADVANCE
DISEASE PATHWAY

SHARP (SEXUAL HEALTH AND
REHABILITATION PROGRAM)

CENTER FOR FATIGUE IN
MEDICAL ILLNESS

INSTITUTE FOR EDUCATION
AND RESEARCH IN PAIN AND
PALLIATIVE CARE

SAN DIEGO HOSPICE CORPORATION

San Diego, California

One of the most frustrating things about working in the hospice movement is having to turn down patients in need — those who are gravely ill but whose prognosis extends beyond six months, the box in which hospice patients must fit, according to Medicare guidelines. San Diego Hospice, a 23-year-old program with an inpatient unit and strong academic connections, has found a way to work outside the box by providing palliative care to seriously ill home-care patients who do not qualify or are unwilling to enter a hospice program.

“Because this organization is so mission-driven, we wanted to take our pain and symptom management expertise and bring it to patients who are seeking more aggressive treatment,” explains Jackie Hay, director of San Diego Palliative Home Healthcare. The palliative program has a census of 40 patients, many of them in mid-life and not prepared to give up on a possible cure. The program uses a separate home-care license maintained by the San Diego Hospice Corporation.

That’s typical of how the San Diego Hospice has grown and innovated in its community — finding an unmet need and filling it. For instance, the hospice has a two-year-old initiative reaching out to people who lose a child during pregnancy or expect their baby to die soon after birth. The hospice’s children’s team, which also cares for terminally ill children and young adults diagnosed in childhood, provides counseling for new parents who find out during pregnancy



their baby won’t survive. “These families had nowhere to turn,” explains Kim Simon, director of communications for the hospice. “Now we help the family prepare for the birth and death of the child at the same time.”

A close relationship with pain specialists at the University of California, San Diego, provides hospice patients with the most advanced pain relief. This supports a practice of aggressive pain and symptom management. San Diego Hospice teaches physicians how to use pain medications appropriately while involving patients in determining their treatment outcomes.

An important part of continuity of care is the customized care plan that is developed for each patient upon admission. It follows the patient across settings throughout the duration of hospice care and is reviewed at least every two weeks. The hospice, which serves more than 2,300 patients each year, has a staff of nine full-time palliative medicine physicians.

The hospice has a comprehensive bereavement program based on individualized care plans. Individual and family counseling, support groups for adults and

children, an 18-month educational grief newsletter program, as well as several other supportive and therapeutic activities are available to families of patients.

San Diego Hospice also emphasizes spiritual care, and has nine chaplains on staff representing a variety of faiths. The staff is rounded out by 360 full- and part-timers and another 375 volunteers.

From early on, the hospice has had a mission to pursue research and education, and offers a hospice rotation and two electives to students at the UCSD medical school. Hospice leaders are involved with the national effort to establish a palliative care curriculum and are dedicated to furthering the field. “We will not just be providing some of the highest quality care in hospice,” explains Simon, “but we will be the pre-eminent hospice where professionals will want to get their training.”



INNOVATION HIGHLIGHTS

**PALLIATIVE HOME HEALTH PROGRAM
FOR SEVERELY CHRONICALLY ILL**

EARLY INTERVENTION PROGRAM

**EMERGENCY PACK FOR FAMILIES TO
TAKE HOME**

**STRONG PHYSICIAN INVOLVEMENT
AND LEADERSHIP**

THE BUTTERFLY PROGRAM
UNIVERSITY OF TEXAS MEDICAL BRANCH

Galveston, Texas

Watching a child die in the intensive care unit, covered in institutional linens and hooked up to high-tech machines and monitors that blink and bleep, is not how most parents would choose to spend their last moments with a beloved son or daughter. And yet, that's what often happens when a child suffers a terminal illness or injury.

An innovative program at the University of Texas Medical Branch (UTMB) in Galveston has eased final hours for such children and families by creating the Butterfly Room.

The Butterfly Room is twice the size of a normal hospital room. There's carpeting, beige paint, and a butterfly wall border. A sleep sofa and comfortable chairs, television, microwave, refrigerator, and coffee maker create a home-like atmosphere. Monitors are removed and the family is encouraged to bring in the child's clothing and music of their choice. Here, the family can carry out its own rituals and be helped through the process by caring health professionals.

"I saw a lot of kids dying in ICU, and they weren't dying in a manner that was very patient- or family-oriented," says Marcia Levetown, M.D., director of the Butterfly Program. "We need to give the family and child the privacy to do what's appropriate for them."

The Butterfly Program is one component of a larger program that Levetown helped establish for UTMB's Children's Hospital, along with two local hospices: Hospice Care Team in Galveston County and the Houston Hospice.

"Doctors and families have a very hard time saying a child has less than six months to live," Levetown says. This



realization often doesn't come until just a few days are left, leaving little time to adjust. Instead, Levetown says, "you need to accept kids who will die sometime during childhood" and provide palliative care, whether or not efforts to prolong life are ongoing.

That's what the Butterfly Program does. Its goals are to increase access to palliative care for children with life-threatening conditions and to help children and families make decisions around continuing life-prolonging care.

Levetown tells the story of one young patient, to illustrate helping a family through the dying process. A 39-month-old child with a degenerative neurological disorder had been hospitalized 39 times with aspiration pneumonia or severe seizures. His mother's heroic efforts had already cost her marriage; her job; her oldest daughter, who ran away; and the emotional stability of her eight-year-old son. Butterfly Program professionals helped the mother accept that she could control the goals of medical interventions for her child, and gradually at her own pace, she wanted him to have symptom relief only. The

boy was able to die peacefully at home with candlelight and music, while social workers helped the mother mend relationships in the rest of her life.

For those considering a similar program, Levetown recommends getting early buy-in from the physicians who will be referring patients. They may be concerned about losing control of their patients and need to understand supportive care adds to, rather than replaces, their care.

Hospitals in San Antonio and Kansas City have adopted aspects of the Butterfly Program for dying children. There's interest in establishing similar places for adults. "If more hospitals adopted it, there would be a big improvement in end-of-life care," Levetown says.



INNOVATION HIGHLIGHTS

STRONG ATTENTION TO DIVERSE NEEDS OF DIFFERENT POPULATIONS AND ETHNIC GROUPS

PEDIATRIC HOSPICE AND PALLIATIVE CARE MEDICATION PROTOCOL

BUTTERFLY ROOM

THE PEDIATRIC "SUPPORTIVE CARE"

"SAVING PENNIES" PROGRAM AT LOCAL ELEMENTARY SCHOOL

AWARD WINNER

IMPROVING CARE THROUGH THE END OF LIFE
FRANCISCAN HEALTH SYSTEM

Gig Harbor, Washington





“**T**his is not about death, this is about life, and the quality of life,” volunteer Haldean Windsor says about Franciscan Health System’s Improving Care Through the End of Life program and the patients it serves.

Committed to helping patients live as fully as possible through the end of life, the program concentrates on reaching patients much earlier than traditional hospice services and on effectively coordinating existing community resources to support each individual and his or her family.

The two-year-old program is simple and low cost with no charge to the patient. Based in clinics, it relies on nurse case managers, chaplains, and volunteers. Nurse case managers coordinate a care plan with the physician. Chaplains visit the patient and family for their spiritual concerns. Volunteers, overseen by a nurse case manager in each clinic, help reach out to the patients. All are well-versed in existing community resources, such as home meal delivery, shuttle services, legal aid, or durable medical equipment.

Immediately after a patient is identified as a candidate for the program by the physician, the nurse case manager calls the patient, talks about what services the program can offer, and gives a single phone number where the case manager can be reached to ensure that medical and other problems are quickly addressed.

Then, a volunteer is assigned to the patient and family. “They get a diagnosis and don’t know where to turn,” Windsor says. “I listen to their needs, and I let them know about the services that are out there. I try to educate them about their hospice benefit. It’s reassuring to them to know that somebody’s reaching out to them and that they’re not left on their own in the system.”

The dedicated cadre of 74 volunteers currently serves more than 400 patients. Even though they agree to contact their assigned patients once a month, volunteers often stay in more frequent contact, says Windsor. For her, contact is more likely to be weekly, and meetings are sometimes over lunch or a visit to drop off groceries. Volunteers also listen to the patient’s life story, validating the patient’s worth.

Volunteers are trained to be vigilant about pain or symptom management, and a nurse follows up immediately. “We deal with it as if it is a crisis,” says Georganne Trandum, the nurse who directs the program. “We talk to the physician, receive an order, call the prescription in, and deliver it if necessary.”

After the initial contact and assignment of a volunteer, the next step in the program is to hold an advanced care planning session, or family conference, where the patient and family are gathered with the primary care doctor, the nurse case manager, and a chaplain. This is the patient’s opportunity to voice preferences for treatment and how to spend his or her final months of life.

“Some of the experiences in advanced care planning sessions have been pretty dramatic,” relates Mimi Pattison, M.D., medical director for the program. “Patients for the first time have the opportunity to tell their families that they don’t want any more aggressive treatment.”

People who have been sick with cancer or chronic heart disease for a long time sometimes feel they are obligated to their families and the medical system to accept whatever treatment medicine can offer, even if it’s painful or futile. “A lot of our program is about choice,” Pattison says. “It’s about true informed consent, making sure patients really understand what their options are.”

A lot of our program is about choice. It's about true informed consent, making sure patients really understand what their options are.



INNOVATION HIGHLIGHTS

SERVICES ARE PROVIDED BY THE SYSTEM, BUT ARE CLINIC-BASED

EXTENDS SUPPORT FOR PATIENTS TO ONE YEAR OR MORE

ADVANCED CARE PLANNING PROCESS

COMMUNITY ORIENTATION

EXTRAORDINARY RELIANCE ON COMMUNITY-BASED VOLUNTEERS

STRONG LINKAGES WITH HOSPICE

In instituting the program, the typical challenge faced by Franciscan was that physicians did not identify patients early enough and the program's services could not be of use for more than a short time. Physicians often find it difficult to make a final determination that a case is terminal until the last several weeks of life.

After some trial and error, though, Franciscan hit upon a formula that works. Physicians in its primary care clinics are given a list of patients seen in the last two months. They are asked, "Would you be surprised if any of these patients died in the next year?" If the answer is no, the doctor is asked to communicate that to the patient and refer him to the program.

Phrasing the question that way makes doctors feel less as if they are placing a death sentence on patients, explains Trandum. "It's a way to say it without saying, 'You're going to die,'" she explains. "A lot of times the doctors know it intuitively, but they aren't skilled at giving bad news."

Doctors can deliver the message that a program is available to help during this difficult time. "The doctor can say, 'I wouldn't be surprised if this was the disease that caused your death, even in the next year, but we have a program that can help you connect with community resources,'" Trandum says.

Trandum would like the program expanded, but it's difficult to get reimbursement for this type of palliative care. Franciscan is working on a pilot program with Regence Blue Shield to reimburse the clinics for one-hour advance care planning sessions. Also, examination of cost avoidance has been initiated with Region 10 Health Care Financing Administration.

The Franciscan program is now in six primary care clinics and one oncology clinic, each of which agrees to take on some financial responsibility for the end-of-life nurse, part-time chaplain, and part-time secretary. Funded with help from grants and foundations, the annual cost per clinic is about \$80,000.

The program has already succeeded in increasing referrals to hospice and extending the length of stay in hospice. Future goals include developing a palliative care consultation service for the system's three hospitals and outlying communities.

Because of its simplicity and low cost, the end-of-life program could easily be replicated by other systems, Trandum says. Franciscan is helping Providence Health System in Portland and Group Health of Washington do just that. Says Trandum, "We'd like to see this program in clinics across America." •

1999-2000 CIRCLE OF LIFE
AWARDS COMMITTEE

CHAIR

Margaret Campbell, R.N., M.S.N.
Detroit Receiving Hospital
Detroit, Michigan

Steve Franey
Portland, Oregon

Paul B. Hofmann
The Hofmann Healthcare Group
San Francisco, California

MEMBERS

Maureen L. Boshier
New Mexico Hospitals and Health
Systems Association
Albuquerque, New Mexico

Mark Kator
Isabella Geriatric Center, Inc.
New York, New York

Thomas R. Reardon, M.D.
American Medical Association
Chicago, Illinois

Stephen Connor, Ph.D.
National Hospice and Palliative
Care Organization
Arlington, Virginia

Sr. Mary Roch Rocklage
Sisters of Mercy Health System
St. Louis, Missouri

Inge B. Corless, R.N., Ph.D.
Massachusetts General Hospital
Boston, Massachusetts

Richard J. Umbdenstock
Providence Services
Spokane, Washington

Linda Edmondson, L.C.S.W.
Oklahoma City, Oklahoma

Lachlan Forrow, M.D.
Beth Israel Deaconess Medical Center
Boston, Massachusetts

For more information on the Circle of Life Award program or to receive materials for future Circle of Life Awards, please e-mail circleoflife@aha.org, call the AHA Office of the Secretary at 312-422-2700, or write the Office of the Secretary, American Hospital Association, One North Franklin, Chicago, Illinois 60606.

