

CIRCLE OF LIFE AWARD



2009



CIRCLE *of* LIFE™

Celebrating Innovation in Palliative and End-of-Life Care

The 2009 awards are supported, in part, by the California Healthcare Foundation, based in Oakland, California, and by the Archstone Foundation.

Major sponsors of the 2009 awards are the American Hospital Association, the American Association of Homes and Services for the Aging, the Catholic Health Association, and the National Hospice and Palliative Care Organization & National Hospice Foundation; the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association are 2009 Circle of Life cosponsors.

INTRODUCTION

For the past decade, the Circle of Life Award has celebrated innovation in palliative and end-of-life care. We are excited to share with you these stories and models of our tenth year of honorees that demonstrate how the reach and quality of palliative and end-of-life care are expanding in communities from coast to coast.

These programs are vital to a coordinated continuum of care — providing value to our patients and our communities by ensuring the right care in the right setting — and exemplify patient-centered care. This year's honorees include large academic medical centers, community hospitals, and hospices in urban, suburban, and rural settings. We hope that their stories will inspire your organizations to develop or improve your programs and services to better serve your communities.

Sometimes wonderful stories from award programs remain untold. In 2009, a sophisticated and groundbreaking program in long-term care and assisted living was visited — the Motion Picture and Television Fund (MPTF) in California. Unfortunately for reasons unrelated to its palliative care program, MPTF is closing its skilled nursing facility, but it is committed to reconceptualizing and expanding its palliative and end-of-life services to serve its beneficiaries wherever they reside. Although the closing of its nursing home precluded formal recognition of MPTF this year, we applaud its dedication and determination to further palliative and end-of-life care.

Thank you to the foundations and organizational and professional associations that support the Circle of Life Awards. These include the Archstone Foundation and the California Healthcare Foundation, based in Oakland, California. Major sponsors for the 2009 awards are:

- The American Association of Homes and Services for the Aging
- The American Hospital Association
- The Catholic Health Association of the United States
- National Hospice and Palliative Care Organization & National Hospice Foundation.

The American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association are 2009 cosponsors.

On behalf of all of these organizations, we thank the hospitals, health systems, hospices, long-term care homes, and community programs that shared with us their palliative and end-of-life programs through Circle of Life Award applications. Their commitment and dedication touches millions of patients and families throughout the nation every year.



Steve Franey
Chair
Circle of Life Awards Committee
2008–2009



Rich Umbdenstock
President and CEO
American Hospital Association

AWARD WINNER

FOUR SEASONS

Flat Rock, North Carolina





Four Seasons Hospice was in the vanguard of the hospice movement, established in 1979 in a scenic rural region with a large population of elderly. It is still true to that heritage today — the organization’s founder, Jean Moulthrop Hoogstra, still works as a volunteer.

In 2002, the board of directors decided to take the organization to the next level, to make it one of the best hospices in the country. The board hired new leadership and physicians who brought palliative care to the local hospitals.

Palliative care received such a positive response from the local medical community, patients, and families that Four Seasons quickly grew from serving 26 percent of all the deaths in its area to 76 percent of deaths.

Four Seasons now has a team of physicians, nurse practitioners, and physician assistants who work in hospitals, nursing homes, assisted living facilities, and homes throughout the community to bring palliative services to patients wherever they may be. In the hospitals, teams are led by physicians and include a nurse, social worker, chaplain, discharge planner, and music therapist.

John Morris, MD, medical director of palliative care for Four Seasons, attributes the quick acceptance to families’ appreciation of the extra attention during a difficult transitional part of life. “Patients really love the attention and guidance,” says Morris, a pulmonologist who came to Four Seasons seeking a better way to help his patients through the stress at this stage of their lives. Illness causes severe physical, psychological, and family stress. Patients and families have found palliative care to provide wonderful support and guidance through the complex medical system during this stressful time.

Morris had worked in the medical community for 15 years as a critical care physician; local physicians trusted him and made referrals to the new team. “I understood the idiosyncrasies of each community physician, that this doctor wanted to be called before every consult and this other doctor wanted to be faxed,” Morris says.

The palliative care team meets each week to discuss the needs of each patient. Those meetings are always educational, Morris says. “As a physician, patients tell you things they wouldn’t tell other people,” he says. “I also learned that they tell the social worker things they wouldn’t tell the physician, or the chaplain things they wouldn’t tell the nurse. So in our team meetings we learn from each other in a synergistic way.”

CEO Chris Comeaux uses advanced leadership techniques to develop a culture of leadership and quality in growing the organization, making the mission and values a part of the staff’s everyday experience. “Most organizations fall into a trap of only looking at finance and growth,” Comeaux says. “You have to have a care plan for your organization, looking at it holistically and focusing on measurable, specific outcomes.”

Administrators meet regularly for training and share stories of the work they do, to keep the focus on the human side. “People often forget to tell their stories internally, and we celebrate those things,” says Comeaux. “We hold each other accountable to our values.”

Patients of Four Seasons have unusual access to cutting-edge treatments through Four Seasons’ collaboration with university researchers at Duke University in Durham, N.C., M.D. Anderson Cancer Center, and a variety of pharmaceutical companies who are conducting clinical trials for end-of-life care, often focusing

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INNOVATION HIGHLIGHTS

LEADING-EDGE PALLIATIVE CARE
DELIVERY IN RURAL SETTING

INVOLVEMENT IN COLLABORATIVE
RESEARCH WITH UNIVERSITY

PALLIATIVE CARE OUTREACH

on symptom control. Janet Bull, MD, hospice medical director, started the research department in 2005 after being inspired by a Duke researcher's presentation. "What's unique about our hospice is we've been able to incorporate research in a community-based program and take it into a home setting," Bull says.

Most of the studies allow patients to participate while they are at home. They can be enrolled and have blood draws and other monitoring there. That allows them to be involved but doesn't add to the tasks that they are facing. "In this population, there's this huge burden of advanced illness that they're dealing with, and it's affecting everybody in their family," notes Bull.

Many patients deeply appreciate the opportunity to contribute to clinical research. "It's added meaning and a sense of legacy," Bull says. "Often they will receive benefits from new medications not yet approved by the FDA but even if the medication may not benefit them, they have a sense of helping others."

Along with trying out new treatments, the research program is also working to track palliative care and hospice patients to better understand their care and be able to analyze them as a group. Four Seasons and researchers at Duke are collaborating on a state palliative care database that now has more than 1,000 de-identified patient records and can track them by symptom, functional status, quality of life, and other parameters. "We'll be able to query this data set and really look at opportunities to improve care," says Bull. "We can compare where there might be a disparity in care by racial, ethnic, or socioeconomic status. It will help define the palliative care needs in our state."

As the project continues, it will gather data from other palliative care programs in North Carolina.

The research work is satisfying, Bull says, "because you're helping the evidence basis for what we do." As an added bonus, the income from clinical research projects helps support palliative care services, for which it is often difficult to get fully reimbursed.

Four Seasons is establishing an endowment to ensure the organization's financial future. It is also looking to expand its service area into a large metropolitan area nearby.

Even as the organization has rapidly grown and added cutting-edge medical and administrative practices to the mix, its approach remains to provide needed care based on what patients need — not on what reimbursement is available.

At the beginning, the organization waited several years to get its Medicare certification because its leaders did not want to design the organization around the Medicare benefit, says Comeaux. "It's all around patients' and families' needs, and they don't always fit neatly into that box," he says. •

GILCHRIST HOSPICE AND GREATER BALTIMORE MEDICAL CENTER

Towson, Maryland/Baltimore, Maryland

One of the ironies of caring for older patients at the end of life is that when they become frail and sick, they are less likely to find the stability they need. An older patient might bounce from a retirement home to a hospital to a nursing home to rehabilitation and back again. This disjointed system makes it tough for a doctor to follow their care.

But elderly people in the Baltimore area benefit from a unique arrangement. The community has a group of geriatricians who maintain formal connections with Gilchrist Hospice Care, Greater Baltimore Medical Center, and an array of about 25 nursing homes, assisted living facilities, and retirement homes.

For those who need hospice care, this allows for a high level of continuity. Doctors are able to get involved with older patients facing life-threatening diseases much earlier because they are already their primary physicians.

“We are a part of the full continuum of care, following our patients from the hospital to nursing or assisted living facilities or their homes,” explains W. Anthony Riley, MD, medical director of both Gilchrist and senior services at the hospital. “It was the vision of hospice that really spurred this unique collaboration with our geriatrics practice, allowing us to better help patients make the smooth transition from one setting to the next, from one type of insurance to the next.”

The doctors often step in to care for patients who have no primary care doctor but are suddenly facing an acute illness. “It’s a critical time for them, and we are there to facilitate the crucial



conversations that follow a terminal diagnosis,” says Riley. Riley was also instrumental in the creation of a separate but related palliative medicine program located at the hospital and funded by Gilchrist Hospice Care.

The relationship between Gilchrist and the Greater Geriatrics medical group is beneficial to both. “It’s a collaborative relationship,” says Catherine J. Boyne, president of Gilchrist Hospice Care. “The biggest growth in our population has come from long-term care facilities. By having our geriatricians in those facilities, patients who should be on hospice are identified sooner and can begin to receive extra care.”

Gilchrist teams that work exclusively in long-term care settings have also been able to educate staff at those facilities about issues surrounding pain control and end-of-life care, Boyne says.

Gilchrist is a full-service hospice that serves about 475 patients each day. It maintains a freestanding inpatient center that is being expanded from 24 to 34 beds. The organization seeks out ways to extend service to patients who

might not fit into typical definitions of hospice, such as those on experimental treatments for their disease.

The hospice, which serves Baltimore and four nearby counties, regularly partners with other organizations to reach out to new groups of people who might need hospice, palliative care, bereavement, and other services. Recently, Gilchrist won an award from the Baltimore County Department of Aging for a series of educational programs at the county’s senior centers that focused on bereavement and end of life.

Gilchrist also maintains a relationship with the ALS Center at Johns Hopkins Hospital and has become expert in caring for patients with the degenerative disease.

And the hospice has launched an outreach effort to area churches to reach underserved populations who may be unfamiliar with hospice. Too often, families tell hospice staff they wish they’d known sooner about hospice services, says Gilchrist’s outreach brochure. “We hope that someday everyone who can benefit from hospice services will know to ask for our help, sooner rather than later.”



INNOVATION HIGHLIGHTS

**FOCUS ON CONTINUITY OF CARE —
GERIATRIC CARE, FACILITY-BASED TEAMS,
AND COMMUNITY OUTREACH**

**MEDICAL HOME APPROACH TO
PALLIATIVE CARE**

COLLABORATION ON ALS

AWARD WINNER

OREGON HEALTH AND SCIENCE UNIVERSITY
PALLIATIVE MEDICINE AND COMFORT CARE PROGRAM

Portland, Oregon





Intensive care unit nurse Senna Pinney, RN, was caring for a critically-ill, young patient whose mother was having difficulty accepting that her daughter might die even before graduating from college.

Even though the mother and daughter weren't ready to be referred to palliative care, Pinney sought help from the Oregon Health and Science University Palliative Medicine and Comfort Care Team (PMCCT), the hospital's experts in helping families with the end-of-life experience.

Pinney was able to get the guidance she needed. "Sometimes we don't know what to say," Pinney says. "I got some really good advice, just to talk to the mom about what her reality is and go from there."

"The Palliative Medicine and Comfort Care Program staff are willing to offer as much or as little as their colleagues, patients, and families need," says PMCCT physician Hugo Richardson, MD. That flexibility is what makes the service so popular and has led to its use in every adult acute and intensive care unit in the large academic medical center in Portland.

"They're so flexible — they don't jam themselves into situations," says Keren McCord, a social worker in the oncology department. "What they really want is to be as helpful as they can be."

Paul Bascom, MD, FACP, who established the PMCCT in 1995 and now serves as the program's medical director, says the flexibility comes from experience and seeking feedback from the caregivers working directly with patients. "In the early years we moved too fast and stepped on toes," Bascom recalls. "We learned when it's important to move fast and when it's important to sit back, provide emotional support to all involved, and wait for things to unfold."

The goal is to enhance communication among the primary medical team, patient, and family throughout treatment and decision-making. Initial requests for help with a seriously-ill patient go to two Clinical Nurse Specialists (CNS) to triage the consult and identify which team members will respond. Usually a CNS and a physician complete the initial evaluation together. "The team strives to respond as quickly as the need dictates," says Mary Denise Smith, RN, CNS, and PMCCT member. "When we are called about a care conference, a patient with uncontrolled symptoms, or a dying patient who hopes to make it home for their last hours or days of life, then we respond immediately."

The team is particularly adept at supporting a patient's values and beliefs in a compassionate way. "The palliative care team has the time and skills," says Pinney. "One might want to live with dialysis and another might want to go home with hospice support. They take the time and seem incredibly present with patients."

Pinney has worked at OHSU before and after the advent of palliative care and describes the differences as "night and day." "Before, when we withdrew life support from a patient in the ICU, there was nothing we could do for the family," she says. "But with the help of the palliative care team, we've started giving quilts and doing handprints, all sorts of creative things. It's been empowering from a nursing point of view. While we can't always make the pain go away or the sadness, we can do things for people that are meaningful."

The program is also remarkable for its efforts to help smaller hospitals throughout Oregon to establish their own palliative care programs. PMCCT member Erik Fromme, MD has organized the effort to establish or grow

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INNOVATION HIGHLIGHTS

FOCUS ON BROADENING PALLIATIVE CARE

STRONG RESEARCH AND EDUCATION ELEMENTS

COLLABORATIVE WORK AND STATE-WIDE EFFORTS

programs at ten other hospitals in the state of Oregon and has grant money to focus on additional smaller and rural hospitals. It has also provided continuing education on the topic to approximately 2,740 clinicians in Oregon through conferences that draw national leaders in palliative care.

OHSU palliative care team members are pursuing research projects that hone in on the thorniest problems in palliative care. For instance, they are studying clinician accuracy in prognostication. Another project is developing a computer tablet that allows patients to more easily communicate their symptoms to their oncologists; research has shown that doctors are often unaware of or mistaken about many of their patients' symptoms.

The OHSU program has also been supportive of a program of its sister organization on campus, the Center for Ethics in Health Care. The center serves as the national hub for dissemination of the Physicians Orders for Life Sustaining Treatment Program (POLST), developed in Oregon in 1991 and growing nationally as a way to ensure that patients' wishes are transferred and respected from one medical setting to another.

Even as the team contributes to the science of palliative care, hospital caregivers are particularly appreciative of a small aspect of the program that has provided great meaning to countless patients and families. Beautiful, multicolored quilts are sewn by volunteers with a variety of different themes and given to patients while they are hospitalized. Families take the quilts home after a patient has died as a remembrance.

Amy Guthrie, PMCCT nurse manager and CNS, has started a volunteer program staffed mainly by first and second-year medical students, who sit by the bedsides of patients and provide trained, compassionate company during the long hours in the hospital. Emanuel Pauwels, a second-year medical student who has served as a volunteer, said one of the most challenging things is learning to sit quietly, if that's what the patient wants.

"After a while you learn it's OK not to always speak, and you let them decide where the conversation goes and what they really want from you," Pauwels says. The experience will help him be a better physician, he believes. "It really has allowed me to connect to patients on a personal level. They share with me parts of their lives they don't usually share with the doctors. You really learn how to read the patients." •

ST. JOHN'S REGIONAL MEDICAL CENTER
ST. JOHN'S PLEASANT VALLEY HOSPITAL
PALLIATIVE CARE SERVICES

Oxnard, California/Camarillo, California

Rachel, a fiercely independent 84-year-old woman, was dying of kidney failure. She'd been through the emergency room several times over the past months, and now her family gathered in the intensive care unit.

Through a palliative care team-initiated conference with family and physician, Rachel's family learned about her poor prognosis. They chose to focus on comfort, acknowledging that she would not want prolonged ICU care or continued dialysis. Rachel transitioned to the hospital's new comfort care suites, her symptoms managed by a palliative care nurse and physician. The family too was cared for: the chaplain relieved the family's anxiety, engaging them in stories about Rachel's life and the legacy; a music therapist played calming flute melodies; the dietary team stocked the comfort suite to provide refreshment and respite.

A social worker helped the family understand that Rachel would die the way she lived — on her own terms — and encouraged self care.

"Palliative care honors the unique journey of each family as they confront the difficulties of advanced illness and the mystery of death; we take their lead and walk with them each step of the way," says Tina Picchi, director of palliative care services for St. John's two hospitals in Oxnard and Camarillo, California. "The image, *Stairs in the Night*, by Janet Fogg, quilt artist, represents this transformational journey."

The team's strength: its transdisciplinary approach to care, balancing the medical, social, and spiritual components. "Each discipline performs together, like members of



a fine symphony orchestra," says Sr. Suzanne Krawczyk, RN, palliative care nursing coordinator.

The program was developed in 2003 as part of a palliative care initiative by hospital parent Catholic Healthcare West. The St. John's team is led by a spiritual care professional and provides a flexible model that gives physicians the option for a palliative care nurse intervention with or without a palliative physician consult. The interdisciplinary team provides a coordinated approach to goals of care, symptom management, and spiritual, emotional, and continuum of care needs, including hospice.

A palliative care physician oversees the clinical management and guides team members in enhancing quality of time for patient and family. Treating physicians appreciate his expertise in addressing the patient's multi-faceted needs. If he does not provide a formal consult, he mentors the RN team leader. "This flexibility allows physicians to use our service in whatever way meets their needs; they often do not need another physician consultant but do benefit from the expertise of our team," says palliative care medical director

Charles Pankratz, MD. Last year palliative care provided services to 780 patients.

The program has championed advance care planning as part of a system-wide initiative. Six years ago only about 25 percent of patients with life threatening illnesses had documented conversations with the care team about their prognosis, options for treatment, and pain and symptom control. This number was raised to 85 percent through extensive education as well as a new electronic documentation tool. "That speaks of a culture change," says Sr. Krawczyk. "People were not consistently having these conversations before."

Supported by grant funds, the program successfully expanded palliative care services in critical care. The St. John's program is seen as a leader in the CHW system and often hosts visitors from other system hospitals.

The advice they give others is simple: Focus on creating a collegial, truly transdisciplinary team. "We created a community of people who are very passionate about this work" says Picchi. "They are very skilled individuals who have been change agents with their colleagues. This advocacy creates a ripple effect throughout the organization."



INNOVATION HIGHLIGHTS

CULTURE OF CARING, INCLUDING PATIENT AND FAMILY-CENTERED CARE

TRANSDISCIPLINARY, DIVERSE PATIENT CARE TEAM

CHAPLAINCY LEADERSHIP

AWARD WINNER

WISHARD HEALTH SERVICES
PALLIATIVE CARE PROGRAM

Indianapolis, Indiana





Gregory Gramelspacher, MD, was an internist caring for patients at Wishard Health Services in Indianapolis in the mid-1990s. He joined the faculty at Indiana University School of Medicine after completing a fellowship in medical ethics. Doing ethics consultation at Wishard Hospital brought him to the bedside of many dying patients.

By the time someone called for an ethics consult, it was often too late to make a difference in how a person died. When a resident physician asked for help to resolve a conflict for a terminally-ill cancer patient because further treatment was futile, Gramelspacher reflected that, “What was really futile was how we teach our doctors. I don’t think patients dying of cancer or any other medical situation should have to die in the intensive care unit after treatment has been withdrawn. The family should have the option of caring for the patient, if possible, at home.”

His sense that there must be a better way to care for people at the end of life came as the palliative care movement was gaining momentum. “I realized that what I should really be doing is preventive ethics consultation, which is essentially a palliative care consultation,” Gramelspacher says.

Wishard serves the county’s low-income populations who are often diagnosed late and then contend with the other serious problems that go along with poverty. “It’s really tough to be poor and also tough to be dying, so to be poor and dying is a very difficult situation,” Gramelspacher says.

In 1995, the Project on Death in America provided Wishard a grant to study the care of terminally ill patients in a public hospital system. This research described the waterfront for the dying poor. With the addition of nurse Jo Groves in 1999, he started the palliative care program at Wishard. Over time, with the support of the organization’s leadership (most notably CEO Lisa Harris, MD) the program added staff, including chaplain Karen Estle; social worker Judy Hetzel; program manager Christine Slater-Turner; executive assistant Brenda Mason; attending physician Lyle Fettig, MD; and fellow Rafael Rosario, MD.

“We sought out the most difficult cases, not only because that was the greatest need, but also because we believed that if we could demonstrate our effectiveness with these patients and their providers, our program would grow quickly,” Gramelspacher explains. This proved to be true — the program grew by 20 percent to 30 percent each year, currently serving about 600 patients yearly.

Visiting Nurse Service Hospice of Central Indiana helps the team’s outreach by agreeing to take patients regardless of their ability to pay. Other local hospice programs also assist in patient care and area foundations provide additional funding.

The program receives philanthropic support from St. Margaret’s Hospital Guild, which raises money to fund the special needs of Wishard’s patients. Past funding from St. Margaret’s supported a nurse practitioner and currently helps with home visits to palliative care patients and their families.

Team members say replication of their work is possible by any health care organization willing to support palliative care. It costs Wishard about \$500,000 each year to operate the program, but the team has documented significant cost savings from palliative care consultation, which more than covers the cost of the service.

For the very low-income people seen by the team, dealing with an immediate diagnosis is secondary to the other crises they face every day. Upon hearing a serious diagnosis, a patient will commonly say, “Well, that’s just another bad thing to

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INNOVATION HIGHLIGHTS

CONTINUITY AND COMPREHENSIVE END-OF-LIFE CARE USING LIMITED RESOURCES

OUTREACH THROUGHOUT THE HOSPITAL AREAS

HOLISTIC APPROACH TO CARE FOR THE POOR AND DYING POOR

happen to me this week.” The Wishard team steps in to assist with life’s everyday problems as well as the emotional strain of living poor, so the medical care can be more effective.

Chaplain Estle is trained as a mental health clinician and finds many patients have to work through “layers” of pain and loss from years of living in poverty before they can start to experience the grief about their own life-limiting illness and move forward with treatment. “I do a lot of grief counseling with people and normalizing it and naming it,” Estle says. “It’s helping them relax and feel like they don’t have to keep butting their head against life. You can’t get to the medical stuff until you’ve dealt with the psychosocial.”

Even then, logistics get in the way. Appointment reminders might never be received because the patient has no permanent address and uses a temporary cell phone. However, the team uses the electronic medical record to alert it when a patient arrives in the emergency room or is admitted to the hospital.

When the team consults on patients estranged from their family, they make the effort to track down siblings or other family members. Most often, both patients and their families appreciate the chance to reconnect.

The program has a strong teaching component so that medical students and residents can learn through direct patient exposure. Wishard’s program also serves as the main venue for the palliative medicine fellowship at Indiana University School of Medicine.

Gramelspacher believes the team’s successful because of members’ commitment. “We’ve found the right people who have a passion for this work,” he says. “Not everyone has the talent to provide care to poor, dying patients.”

The work can be challenging, but there is also an opportunity to make a real difference. For instance, nurse Groves recalls a homeless patient known as Cowboy who slept under a bridge most of the time. When Cowboy was hospitalized at Wishard for lung cancer treatment, he often disappeared, and the doctors didn’t know where to find him. The palliative care team tracked him down and found that he left the hospital to feed and care for his dog, Cowgirl.

The palliative care team found a place for Cowboy to stay so that he could die in comfort, with his best friend. “When I close my eyes and think about why this work is worth doing, I remember Cowgirl lying on Cowboy’s chest as he was taking his last breaths,” says Groves. “I thought, ‘OK, this is why we do this work.’” •

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