

CIRCLE OF LIFE AWARD



2014



CIRCLE *o f* LIFE™

Celebrating Innovation in Palliative and End-of-Life Care

The 2014 awards are supported, in part, by the California HealthCare Foundation, based in Oakland, California, and Cambia Health Foundation. Major sponsors of the 2014 awards are the American Hospital Association, the Catholic Health Association, and the National Hospice and Palliative Care Organization & National Hospice Foundation. The awards are cosponsored by the American Academy of Hospice and Palliative Medicine, the Hospice and Palliative Nurses Association & the National Board for Certification of Hospice and Palliative Nurses & the Hospice and Palliative Nurses Foundation, and the National Association of Social Workers.

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INTRODUCTION

What does great care look like? The 2014 Circle of Life honorees showcase how palliative care helps meet the Triple Aim. Palliative care strengthens evolving health care systems as they collaborate with community-based services to meet the complex needs of people and their families living with serious and progressive illnesses. Health care providers from hospitals to hospices recognize that services best meet the needs of those who are very ill when provided in a continuum across all sites of care delivery, particularly in the home. The challenge and the goal are to provide the best care possible to patients and family in a timely and effective way. Our honorees give us insights and inspiration to meeting these complex needs.



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AWARD WINNER

BAYLOR HEALTH CARE SYSTEM SUPPORTIVE AND
PALLIATIVE CARE SERVICES

Dallas, Texas





One of the greatest losses for a dying person is giving up food and water when swallowing becomes difficult. At that point, typically, the patients get artificial nutrition administered through a tube, which doesn't give pleasure and doesn't really help the patient. Recognizing the emotional resonance of meals to both the patient and family, Baylor Health Care System's Supportive and Palliative Care Services (SPC) collaborated with the Speech Therapy and Nutrition departments to develop a program that teaches families how to provide simple foods such as ice cream to their dying loved one, avoiding the insertion of a feeding tube.

"It's a very loving thing that families can do," explains Robert Fine, MD, FACP, FAAHPM, clinical director of SPC, "and poses no more choking risk than that of saliva. Patients and families alike prefer this approach."

The comfort feeding program is just one of a number of changes in hospital practice the SPC program has implemented. No change has been more important than adding the term "supportive care." "We started out as the Palliative Care service but when we rebranded as Supportive and Palliative Care, early consults, including outpatient referrals, grew dramatically," says Fine.

Baylor's SPC program grew out of a clinical ethics program providing about 120 collaborative clinical ethics consultations yearly, most at the very end of life. The ethics consultation team could help negotiate a care plan, but could not treat pain or other suffering. Recognizing the need to reach seriously ill patients earlier, the Palliative Care program was launched in 2004.

Baylor has been described as a "learning organization" that welcomes innovation and has undergone significant cultural transformation to embrace palliative care as distinct from hospice. Leadership has supported the goal of four-core-discipline (physician, nurse practitioner, social worker and chaplain) Joint Commission certifiable palliative care teams for each acute and chronic care facility (two teams are already certified) as well as multiple options for community-based ambulatory palliative care.

Ambulatory palliative care currently includes two outpatient SPC clinics, providing both new patient same day appointments for pain and hospital follow-up, ensuring continuity of care for discharged patients and often preventing unnecessary admissions. Fine has worked with the director of the long-established Baylor House Calls program, a service providing care for about 1,200 homebound elders, to build comfort care and symptom management resources. "That doesn't require a new investment; it's a coordination of investments that already exist," explains Fine.

Collaboration and synergy with the broader community is important to Baylor and apparent in outreach to extended care facilities and the African-American community. Baylor developed a MOST form (Medical Orders for Scope of Treatment, based on the POLST paradigm) and has helped train both hospital and extended care facility staff to use the forms for care planning and communication. Baylor has also worked with a local hospice (VITAS) to provide primary care and cardiologist education about the role of palliative care and hospice in advanced heart failure. To promote better understanding of differences between palliative care and hospice within the African-American community, SPC leadership organized other Dallas-Fort Worth health care providers to bring the APPEAL program, a palliative care education curriculum for African-Americans, to North Texas, raising \$25,000 in scholarship funds for nursing home and church workers in the African-American community to attend and learn.

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INNOVATION HIGHLIGHTS

AMBULATORY PALLIATIVE CARE

SUPPORTIVE CARE FOCUS

SYSTEM CULTURAL TRANSFORMATION

Synergism with the critical care and emergency department led to development of “trigger tools” to systematically identify their SPC-appropriate patients. The results: more palliative care consults on admission from the ED, more direct hospice admits from the ED, and shorter ICU lengths of stay.

Spiritual care is a key component of palliative care. “Sooner or later, our mortality is no longer a medical problem to be solved; it is a spiritual problem to be faced,” says Fine. Chaplains are active members of every SPC team, using a spiritual assessment tool to better identify patient and family needs. The tool explores the patient’s faith tradition, coping ability, what they understand about the treatment plan and whether they agree with it. “We ask how they heard what the doctor said, which may be quite different from what the doctors have told them,” explains Rev. Dr. Marci Pounder, senior SPC chaplain. Sometimes patients will divulge to chaplains information they won’t share with a physician or nurse.

Rev. Pounder also recruits, trains, and oversees volunteer doulas to accompany and comfort the seriously ill and dying. They offer practical and spiritual companionship, making 2,748 visits in fiscal 2013. “Doulas can sit with a patient all day,” Rev. Pounder says. “Sometimes they just want a presence, a good listener who can just sit there and hold their hand.” Some patients and families are also more candid with a volunteer doula than with a medical professional.

Dr. Fine and his administrative partner, Martha Philastre, MS, MBA, FACHE, are particularly proud of SPC Child Life services. Fine says he realized early on that neither he nor other team members had the expertise to support key family members, the children of seriously, often terminally, ill adults. “We had a 40ish year-old man dying of pancreatic cancer, and I was called in to help with his pain,” recalls Dr. Fine. “Not only was he in severe pain, he was dying. I was so focused on the pain I hadn’t even thought about children, until both patient and wife asked what they should tell their two boys, eight and 10. The kids hadn’t been told anything, and the patient and his wife asked me to speak with the boys.” Dr. Fine remembers feeling “incredibly inadequate” and resolved to make changes. Money was raised to hire a child life specialist and under the leadership of Cinda McDonald, MEd, CCLS, GCCA-C, the program has grown to four specialists across the system, providing support to 703 children coping with the loss of a parent or other loved one in 2013. •

CENTER FOR PALLIATIVE AND SUPPORTIVE CARE,
AMBULATORY PROGRAM
UNIVERSITY OF ALABAMA AT BIRMINGHAM

Birmingham, Alabama

A person contending with the ups and downs of a complex serious illness spends most time at home, not in the hospital. That's why the ambulatory setting has become a priority for the Center for Palliative and Supportive Care at the University of Alabama, Birmingham, which is developing an array of palliative and supportive care outside of medical facilities.

"If we are focused only on inpatient palliative care, we are missing our population until it is really late in the game," says Elizabeth Kvale, MD, medical director for outpatient palliative care.

The UAB's Center for Palliative and Supportive Care maintains a strong inpatient program for hospitalized adults, children and veterans but in recent years has branched out to provide care wherever people need it, explains Rodney Tucker, MD, the center's director. "We're extending the care model further upstream in the lifecycle of the patient, extending what we do earlier in the diagnosis and more broadly for patients and families."

The ambulatory program provides care in two outpatient clinics, at home and via telemedicine. It offers support from navigators as well as building community support teams from the patient's family and friends. "We maintain many layers of many safety nets," explains ambulatory program Director Jennifer Hicks, MSHA, MBA. "It all goes hand in hand, and as patients go back and forth we're able to follow them through the entire serious illness trajectory."



The center has built the ambulatory care program by being open to trying new ideas and adopting the ones that work. Each piece may have a different business model — some are paid by grants, some by philanthropy, others supported by the UAB health system. The program's community advisory board helps to build ties to the community, and its members (who represent wide-ranging backgrounds including faith leaders, civic organization leaders and industry leaders) have been instrumental in finding funding for specific programs and making connections that lead to new services for patients and families.

The program has a number of innovations. For example, an interdisciplinary team in the outpatient clinic (and a second clinic focused specifically on HIV) sees patients with all disease types who have advanced illness. The team includes a wide array of services including mental health, physical therapy, massage, spiritual counseling and dietician services. Also, community health workers with training in palliative principles help patients use the health system, advocating for

symptom management and other supportive care. Many of these workers are drawn from traditionally underserved communities. In addition, in an effort to help patients and families have advanced care planning conversations earlier in the trajectory of illness, the program has its community health workers and nurse navigators initiate these conversations with patients diagnosed with cancer across a five state network in the Southeast. The Supportive and Palliative Advocacy Resource for the Community (SPARC) Program trains professional cancer navigators to train community health advisors specifically in psychosocial support for women with breast cancer, and the center has taught physical trainers in the community about exercise specifically for cancer patients and survivors.

The palliative care program extends its reach beyond the professionals by enlisting the support of the patient's family and friends, who want to help but may not know how. They are organized as an "organic support network" by a team coach, recognizing that the patient may not have the energy to assign tasks. "It allows people to do the things they want to do and love to do in service to someone they care about," explains Dr. Kvale.



INNOVATION HIGHLIGHTS

AMBULATORY PALLIATIVE CARE

COMMUNITY HEALTH WORKERS

COMMUNITY SUPPORT TEAMS

AWARD WINNER

LEHIGH VALLEY HEALTH NETWORK

Allentown, Pennsylvania





So many palliative care providers wish they could have reached a patient earlier in their illness. Lehigh Valley Health Network identifies patients with serious illness early and sends nurse practitioners to visit them at home, often for years. Using strong linkages with primary care, the palliative care program reaches patients early in diagnoses for illnesses such as dementia, Parkinson's, MS, congestive heart failure, COPD and cancer. "We're seeing some patients for three to five years," says Gretchen Fitzgerald, CRNP. The average length of stay is eighteen months.

Fitzgerald believes time itself is a tonic and helps patients come to grips with their new reality one visit at a time. She recalls a man suffering from end-stage cardiac disease, COPD and renal failure. "He really wanted to stay home and out of the hospital, but he wasn't emotionally ready for hospice," says Fitzgerald. "After months of visits to his home and a lot of conversation, he was diagnosed with cancer. He chose not to pursue treatment and to enter hospice and died a month later at home."

Fitzgerald is convinced that all those conversations in the man's home about his values and beliefs were crucial to making the right choice for himself and his family. "When you go into someone's home people are much more honest, they are more insightful, because they feel comfortable there," says Fitzgerald, one of six nurse practitioners who makes home palliative visits.

Today Lehigh Valley Health Network's palliative medicine program, OACIS (Optimizing Advanced Complex Illness Support) spans the full continuum of care, with an inpatient consult service, outpatient clinic and home visits. Its roots reach back to 1999 when senior physicians received a grant for an inpatient palliative care consulting service and another specifically for the ICU, explains Dan Ray, MD, medical director. They also linked with a project focused on serving medically complex patients in primary care. In 2006, the network held a two-day retreat, inviting a broad spectrum of stakeholders, including patients and families, primary care and specialist physicians, community members, benefactors, hospital administrators and third-party payers, which resulted in a strategic initiative for palliative care for the entire network.

Involving all parties from the start was key to developing a sustainable palliative care program across the continuum, Ray says. And it has paid off so that now, years later, there are multiple partnerships to better serve this population. "We recognize the importance of taking the time to reach out to others providing care," he says. This includes connections between the inpatient service and the outpatient providers, across the palliative care continuum.

Those connections extend into the community in novel ways that support people with serious illness. Clinical Coordinator Barb Sikora ticks off a long list of organizations and agencies she has reached out to: parish nurses, church volunteer groups, welfare office case managers, specialty clinics, ambulance companies, nursing home social workers, the public housing authority, even the coroner's office. She is on the phone pretty much constantly, making connections with both clinical and social resources. "The 5 percent to 10 percent sickest patients in the hospital system don't have a lot of resources," she says. "It may be social, it may be economic, we look at how we can be creative in connecting to resources they need."

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INNOVATION HIGHLIGHTS

COMMUNITY-BASED PALLIATIVE CARE

DUAL LEADERSHIP STRUCTURE

COMMUNITY EXCHANGE TIME BANK

The OACIS home-based program benefits from collaboration with Community Exchange, a time bank that is part of the health network's community health department. Through the time bank, volunteers can exchange services with one another, such as companionship, light house and yard work, medication pick-up, rides to medical appointments, shopping and caregiver respite. OACIS patients and family members can become active members in the exchange, reducing their social isolation and also giving them the dignity of being able to give back to others.

With strong leadership by physicians and nurse practitioners who practice at the top of their licensure, it's not surprising that education is a critical part of the program, with an accredited Hospice and Palliative Medicine Fellowship along with Palliative Medicine Scholars, a program that has provided education and culture change throughout the organization and gives clinicians and staff interested in palliative care a venue for connecting and supporting each other.

Program Director Donna Stevens believes a major strength of the program is its dual leadership structure which has resulted in a well-integrated clinical service with a strong administrative foundation ensuring the services are sustainable. "This partnership enables us to negotiate the many challenges involved in establishing and sustaining a robust palliative care service. Lehigh Valley Health Network values and supports this dual leadership model," Stevens says.

Managing the full continuum requires oversight. "Home-based anything is becoming quite complicated now by virtue of the number of programs and services that have been put in place to address the needs of this very sick population," Stevens says. "It has certainly complicated our home-based business significantly over the years, but it's really very necessary."

Lehigh Valley has reorganized to be more longitudinal, notes Sue Lawrence, senior vice president for Care Continuum. It's all part of an evolution toward managing populations in an accountable way, and the OACIS program providing support for patients with complex illness and chronic conditions is an essential part of the strategy. She credits the physician leaders who developed OACIS with providing the network with a path to the future and better care for seriously ill people. "As a network we have been blessed with some leaders who had a vision for the future and recognized that together these siloed groups could achieve much more than each individual group could achieve on their own," she says. "They provided the platform for us to stitch all this together." •



AWARD WINNER

YAKIMA VALLEY MEMORIAL HOSPITAL
AND FOUNDATION

Yakima, Washington





Take a map of Washington state, point to the middle and down a bit, and you'll find the city of Yakima, and not much else. Yakima County is quite rural; the Yakima Indian Reservation comprises one-third of the county, and the rest is either mountains or farms (growing fruit, wine grapes and cows). A fifth of the county's population lives below the poverty line and 65 percent of Yakima Valley Memorial Hospital's patients are on Medicaid or Medicare. This is not a place where community hospitals can afford to throw a lot of money at new ideas in health care delivery.

And yet, Memorial and its foundation provide their community with sophisticated, caring patient- and family-centered palliative and end-of-life care. They've done it by tapping into the community's own commitment to improving the quality of life in central Washington.

"This is a small community," notes Memorial Foundation President Anne Caffery. "To have many of the things large communities have, people here have become accustomed to cross-training, collaboration and punching above our weight. By necessity we have gotten very crafty and can-do about sharing tasks."

The growth of hospice and palliative care reflects Memorial's culture, nurtured by former hospital CEO Rick Linneweh. Caffery recalls when he suggested they look at the criteria around national award programs such as Circle of Life and AHA NOVA Awards to set goals for the organizations. "He said he wasn't as concerned about getting the awards as about keeping the criteria in front of us so we know what to aim for," she says.

A steering group of hospital staff and volunteers in the early 2000s examined needs around end-of-life care in the region. The results included a major fundraising campaign to build a hospice house and the creation of the largely volunteer *Transitions* palliative care program, an outpatient program serving more than 200 patients each year in their homes, staffed by a social worker and volunteers.

Transitions is an example of a program that gets a lot of value out of a small investment. A few staff members who were interested in getting a palliative care program off the ground wrote a proposal for a pilot that would cost \$26,000 and were funded. A couple of years later they wanted to expand the idea and needed \$52,000. "We didn't have enough, so we went out and found two donors in the community who split that," recalls Caffery.

Transitions now serves about 70 to 80 patients at any given time and uses minimal resources — just a half-time social worker, a Jesuit volunteer leader and a large cadre of trained and enthusiastic volunteers. When needed, the volunteers seek assistance from a home health social worker or the liaison nurse for hospice and refer medical questions to the patient's physician.

Hospice was begun in the home setting in 1995, but Memorial recognized the need for a "place" for hospice patients rather than re-hospitalization. The Cottage in the Meadow Hospice Care Facility became a community-wide effort. It took about five years to raise the \$5 million needed to build the facility, explains foundation board member Royal Keith. Despite the Yakima area's moderate population and relatively low median income, the hospice center was built solely with contributions from Yakima's business community and 6,500 individuals.

Nurses from the hospital are cross-trained to work in the hospice house, bringing palliative care expertise to the inpatient setting, and pharmacists at Cottage have authority to change some medications without a physician consult to ensure rapid care and address critical symptoms, such as pain or nausea.

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INNOVATION HIGHLIGHTS

COMMUNITY PARTNERSHIPS

RURAL OUTREACH

SPIRITUAL CARE AND LEADERSHIP

Memorial's end-of-life program takes a holistic approach, addressing not only the patient's care needs but also the needs of family, whether it's a children's play area at the hospice house or a grief support group, says Patrick Waber, MD, Cottage medical director.

The program has 187 volunteers, including a dozen high school students and 10 military veterans. "Many of our volunteers have experienced a loss and now are ready to give back. There's just a passion that's developed," explains Carolyn Neiswender, director of Home Care Services. Volunteers also provide bereavement care to families who have had a loved one in Memorial and to others in the community. The program also has provided bereavement training to school counselors, as well as a bereavement program specifically for children.

The foundation promotes an ongoing community conversation about palliative and end-of-life, with a steering committee including a wide array of experts such as clinical staff, attorneys, financial advisers, organ donation specialists and many more. They meet to share expertise and put on monthly talks on topics such as living wills, veterans' concerns, coping with grief during the holidays and cross-cultural issues.

The program's spiritual care side provides support for patients and families but has gone further and is training the area's clergy as adjunct end-of-life support. About half of the 280 community clergy members in the Yakima area have been through a three-hour training to learn what the end of life looks like and how to help people through it.

The program recognizes the multicultural aspects of the Yakima area, where 46 percent of residents are Hispanic and nearly 6 percent are Native American. A bilingual Jesuit volunteer speaks at local churches about end-of-life issues and cultural barriers to using hospice, and Memorial's Community Health educators work to educate Latinos about hospice on Spanish-language radio and television. The program is working with the Yakima tribe to learn cultural issues around end of life for that community. It also provides care at Yakima's homeless shelter and works with its federally qualified health centers.

Yakima Memorial's palliative care program could be replicated in any rural area with limited resources. "We have not tried to reinvent the wheel here," explains Laurie Oswalt, Memorial's director of spiritual care. "We're taking what works well from other places and applying them in different ways here so it does become unique to us. Any community can take what we've done and make it theirs." •

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, 155 North Wacker, Suite 400, Chicago, Illinois 60606.

