

CIRCLE OF LIFE AWARD



2019



CIRCLE *o*f LIFE®

Celebrating Innovation in Palliative and End-of-Life Care

The 2019 awards are funded, in part, by the California Health Care Foundation, based in Oakland, CA, and Cambia Health Foundation, based in Portland, OR. Major sponsors of the 2019 awards are the American Hospital Association, the Catholic Health Association and the National Hospice and Palliative Care Organization and National Hospice Foundation. The awards are cosponsored by the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice & Palliative Nurses Association/the Hospice & Palliative Credentialing Center/the Hospice & Palliative Nurses Foundation, and the National Association of Social Workers.

The Circle of Life Award is administered by the Health Research & Educational Trust.

Imagine falling asleep to your father's heartbeat. Imagine receiving care in your native language despite leaving your homeland. Imagine meeting a caregiver who offers choices when you believed you had none left. This year's Circle of Life Award honorees enable these experiences and much more. Their passionate, creative teams deliver care and education in rural areas, ensure a high quality of life for children, utilize new payment models, and develop new disease-specific clinics, all while supporting patients' families. They are multifaceted yet laser-focused on delivering comprehensive, compassionate care. Imagine that.

Please read their stories to learn more and join in the Circle of Life celebration of innovative palliative and end-of-life care programs that:

- Serve people with serious and life-limiting illness, their families, and their communities.
- Demonstrate effective, patient/family-centered, timely, safe, efficient, and equitable palliative and end-of-life care.
- Use innovative approaches to meeting critical needs and serve as sustainable, replicable models for a segment of the field.
- Pursue quality improvement consistent with the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, NHPCO Standards of Practice for Hospice Programs or other widely accepted standards, within their resources and capabilities.
- Address biomedical, psycho-social, spiritual, and cultural needs throughout the disease trajectory.
- Use innovative approaches to reach traditionally underserved populations.
- Actively partner with other health care organizations, education and training programs, the community, providers of care, and/or insurers.
- Use metrics that demonstrate significant impact and value for individuals, families, and communities.

More information about the Circle of Life Award, complete award criteria, and past recipients are available at www.aha.org/circleoflife.

AWARD WINNER

HOSPICE OF THE WESTERN RESERVE
NAVIGATOR PROGRAM

Cleveland, Ohio





When Karen's husband Donald was diagnosed with ALS at the age of 61, the devastating news came after a frustrating year of misdiagnoses. The couple soon went to an ALS support group meeting to try to make sense of the disease and what they might expect. At the meeting, a speaker from the Hospice of the Western Reserve mentioned the Western Reserve Navigator palliative care program.

At that time, the couple was overwhelmed by the idea of ALS, a little frightened by the word "hospice," and wasn't ready to consider palliative care. "We backburned it at that point, thinking, 'We don't need that,'" Karen recalls. But after her husband's steady decline, that changed. "A year and a half later we said: 'We do need that,'" she says.

She contacted the Western Reserve Navigator program, which sent a nurse practitioner to evaluate her husband's condition. Even though they'd lived with the diagnosis for more than a year, it was still hard to take in all the ramifications of the degenerative disease and what course it might take. Physicians had been reluctant to give them a detailed prediction because of the variability in how ALS progresses in different people.

But their nurse practitioner, Brandie, provided helpful context and explained that they had choices about how Donald would spend his final years or months and that they should be putting those wishes in writing. "We were pretty clueless about all of that," Karen says. "We never realized we had choices."

The couple's experience is typical of what the program has been doing for 17 years. As one of the nation's first community-based palliative care programs, its teams are able to follow patients and families through all different settings of care, offering support and consistency. Patients and families can contact the program 24 hours a day, seven days a week, with any question or concern.

Judy Bartel, MSN, chief clinical officer, started the program after hospice leaders realized that 20 percent of the calls that came into the hospice referral office were looking for help with symptom management or goals of care for patients who were not eligible for hospice. "At the time, nobody was doing community-based palliative care, so we had no guidance to go by," Bartel recalls. "We had to create it every step of the way."

Using the multidisciplinary team model of hospice as an example, the program grew quickly. "We built it year by year with just good, sound practice of care in the home," she says. "What I'm most proud about the program is it wasn't a fly-by-night thing. It's 17 years later, and it's still sustainable. We take care of 600 patients every single day."

Bartel is particularly proud that the Western Reserve Navigator Program follows National Consensus Project guidelines for palliative care, rigorously analyzing data and working continuously on quality improvement. "You have to constantly be evaluating those domains of care to be sure you have the best practice," she says. The program's parent, Hospice of the Western Reserve, developed its own in-house software called True North that offers granular analytics ability to answer deep questions about how the program functions.

The Western Reserve Navigator program is sustained through the revenue of nurse practitioner visits and the indirect revenue of earlier hospice referrals. And its leaders are pursuing value-based payment options such as shared savings with insurers.

Everybody has the opportunity to share their concerns, observations, and best practices.



INNOVATION HIGHLIGHTS
FULLY INTEGRATED VOLUNTEER PROGRAM
CULTURE DRIVEN BY CORE VALUES
IN-HOUSE SOFTWARE AND ANALYTICS

Bill Finn, CEO of the hospice organization, says its devotion to its values and culture is one reason for its success, growth, and ability to adjust with the times. “We call our culture our ‘invisible architecture,’” he says. “It’s the vehicle through which all things come to life.”

Finn and other leaders are hands-on, regularly filling in as aides and other support positions to better understand the organization from all perspectives. “We try to view the organization as flat, and everybody has the opportunity to share their concerns, observations, and best practices so we can gain the benefit of that,” he says.

Medical Social Worker Sheila Thomas says she’s appreciated the supportive environment. She was invited to present at a team-building day, explaining what social workers do and sharing some of her own personal story as well. “They want to draw out our strengths, our ability, our talents, and to feel comfortable sharing those with everybody,” Thomas says.

The Western Reserve Navigator program maintains a robust volunteer program that provides a wide variety of services to patients and families. Volunteers receive comprehensive training to prepare them to recognize changes that could warrant intervention. The volunteers are an integrated part of the palliative care team, which includes an advanced practice nurse, social worker and volunteer, explains Edie Nelson, a volunteer service manager for the program. “They are an essential part of the program and have been integrated from the beginning,” she says.

Among the services provided by volunteers are companionship, respite support, transportation, legal assistance, errands, light housekeeping, support phone calls, haircuts and reiki. There’s a special group of veteran volunteers who visit patients who are also veterans.

Karen and Donald also benefit from the volunteer program. They have a volunteer named Barb who comes to their house for a few hours of respite care every week to give Karen the chance to go to ukulele lessons. During one visit, Barb noticed Donald was having trouble breathing. Based on her training, she knew to report back to the clinical team, who were able to acquire additional equipment and provide treatment to meet his needs. Karen was grateful that Barb had a deep sense of compassion and urgency in supporting her and her husband. “We so appreciated that Barb had that training,” she says. •

AWARD WINNER

UNIVERSITY OF COLORADO HOSPITAL
PALLIATIVE CARE PROGRAM

Aurora, Colorado





The most agonizing part of the sick father's serious illness was the thought of leaving his young children behind. But with the assistance of a music therapist, he was able to give them a recording of his usual bedtime routine with his daughters, with the sound of his heartbeat in the background.

"It was something they can hold onto for the rest of their lives," says Angela Wibben, a board-certified music therapist who is part of the creative arts therapy program with the University of Colorado Hospital (UCH) Palliative Care Consult Service.

Wibben works with Amy Jones, a palliative care board-certified art therapist, to provide families with a tangible part of their loved one after they're gone. Music therapy may include helping patients write songs to their families, while art therapy may produce a photo collage or legacy jewelry containing the patient's heartbeat tracing or fingerprint.

Their work goes beyond assisting people with creating art and using it for their emotional benefit, Wibben says. "[Our] work lies in the therapy piece of it," she explains. "We often say it's not about the product, it's about the process."

An evaluation of the creative arts therapy program found it improves patient-reported pain, anxiety, and well-being, and enhances quality of life through an emotionally therapeutic effect. Wibben and Jones are developing creative art therapy outpatient workshops for patients, families, and caregivers, and they have produced two iBook compilations of patient and family creations called "Creative Connections."

The creative arts therapy is one of Chief Medical Officer Jean Kutner, M.D.'s favorite parts of UCH's innovative palliative care program. Kutner started the palliative care program at UCH in 2000 as the first hospital-based palliative care program in Colorado and among the first in the nation.

"It really came out of the realization that there has to be a better way to care for the patients in our hospital and our families that have serious illnesses," Kutner says. The program began as four physicians who volunteered their time; hospital leadership was supportive of the idea but couldn't provide any funding. Eventually, they brought on an advanced practice clinical nurse specialist who served as the "heart and soul" of the team, Kutner says.

"We've incrementally grown since then, with that focus of always measuring what we do so we can demonstrate our outcomes," she says. "Our team culture and interdisciplinary approach is one of our significant strengths."

The program continues to innovate with a goal of spreading palliative care competencies far and wide. For example, the University of Colorado welcomed Amos Bailey, M.D., professor of medicine, whose vision was to create a master's degree in palliative care that would be open to all types of health care providers, not just physicians. Designed to appeal to mid-career professionals, the program enables them to do much of the coursework online. The first group graduated in 2018 and included physicians, nurses, physician assistants, pharmacists, social workers, psychologists, and others.

"We emulate the experience of the palliative care medical fellowship," explains Bailey, who directs the master's program. The online curriculum consists of videos of eight different patient and family scenarios that the students must navigate. They spend two years in the program, with three in-person training sessions. The idea is to spread high-quality palliative care training beyond the small number of physician specialists who are produced by palliative care medical fellowship programs. "The advantage to this kind of program is you can scale it to as many people as are

Our collegiality in working together translated to seeing how we could bring quality palliative care to reach more people, even when it's outside of our institution.

interested,” he says. While UCH has three palliative care medicine fellows each year, the master’s program already has graduated 56 students. An offshoot of the master’s program is another innovation: a demonstration project that would allow physicians to use the curriculum as part of an alternative training pathway to become eligible for board-certification in palliative care.

UCH also supports training in spiritual care through a clinical pastoral education fellowship. The training is based on a medical residency but is for people training to be chaplains in palliative care. “The fellowship is specifically for people with a passion for palliative care,” explains William Jensen, a palliative care chaplain at UCH. “Even if they don’t end up in this field, the interdisciplinary experience is huge. They learn goals-of-care conversations, working as part of the team, and they gain a lot of insight into patients’ experiences.”

Along with maintaining a 24-hour palliative care consult service for inpatients, the program provides services through a palliative care clinic and via telehealth through a partnership with a rural community hospital. In another innovative move, UCH developed a neuropalliative care clinic dedicated to the needs of patients and families affected by neurological illness.

Even as the UCH team finds new and meaningful ways to help patients and families, its strength lies in the team’s truly interdisciplinary and unique approach, says Jeanie Youngwerth, MD, director of the palliative care service. “We get interested in doing things that maybe haven’t been done before or ask how we can improve something to make a smoother process,” she notes. “We make sure everything is practical and bring it back to the patient-care level.”

She cites the rural outreach telehealth program as an example of the UCH team problem-solving. While partnering with a small, remote hospital with a cancer center that serves people living in a large, mountainous area, the UCH team wanted to collaborate to bring specialty-level palliative care to rural areas that did not have specialists.

“Initially we were thinking maybe we could have UCH palliative care providers go to the rural hospital, but that’s three and a half hours away and was not practical,” Youngwerth says. Instead, they worked with a physician assistant at the rural hospital to create the telehealth palliative care inpatient service. It is composed of rural hospital advanced practice providers and social workers and chaplains working together with UCH palliative care board-certified physicians via telehealth to bring an interdisciplinary palliative care team to the bedside. Several of the rural practitioners also have signed onto the palliative care master’s program at UCH to become palliative care community specialists.

“Our collegiality in working together translated to seeing how we could bring quality palliative care to reach more people, even when it’s outside of our institution,” she says. “As the rural hospital team members become more fluent over time and more experienced with palliative care, they will become a self-sustaining interdisciplinary palliative care service, won’t need the board-certified doctors from the university, and can deliver palliative care as their own specialized team.” •



INNOVATION HIGHLIGHTS

NEUROPALLIATIVE CARE CLINIC

USE OF TELEHEALTH TO PROVIDE CARE AND TRAINING IN RURAL AREAS

MULTIFACETED PALLIATIVE CARE EDUCATION

AWARD WINNER

UNIVERSITY HEALTH SYSTEM

San Antonio, Texas





As a safety net hospital near the southern U.S. border, University Hospital in San Antonio, Texas, serves a complex patient population whose needs bring unique challenges, especially at the end of life. The teaching hospital has built a comprehensive palliative care program that brings culturally sensitive care to all its patients regardless of funding, residency, or citizenship.

“We tend to have the unfunded, undocumented, un-everything,” notes Julianne Eddy, RN, director of palliative care services. “We don’t really have a criteria on what your social situation is — we believe everyone who needs us should get us.”

The hospital’s palliative care program connects to the immigrant population through a community Promotores program, which employs Spanish-speaking laypeople as health care outreach workers. The Promotores help ensure that people who are worried about their citizenship status get the care they need. “When you’re undocumented and you need procedures and medications, that’s on top of the difficulty of managing clothing, food, and the necessities of living,” says Erin Perez, DNP, palliative care nurse practitioner.

“In our hospital, we get not just people from San Antonio but also people from all the surrounding counties and our neighbors from Mexico who seek out our specialists,” she notes. “Palliative care is one of those specialties. We’re able to provide continuity of care and have those complex conversations to make sure we’re addressing their psychosocial needs in addition to the physical needs. We truly treat the whole patient and family, where they are,” says Perez.

The program’s chaplains are another important conduit to the immigrant and undocumented communities. Through their work, the chaplains have developed a manual describing various cultures and religions, which can be used as a resource as end of life approaches and shared with other organizations.

In addition to UHS’ deep cultural competency, the program has designed team care for specific patient populations: there is an adult-geriatric palliative care team, a pediatric team, and a perinatal team. Recognizing that teenagers with serious illness face a challenging transition from pediatric to adult medical care, the program also developed an adolescent/young adult program, which is a bridge between the pediatric and adult teams.

Another source of assistance for young people comes from Rebecca Charlton, a child-life specialist. She provides developmentally appropriate support not just to children who have serious illnesses but also to the children of families in which an adult is facing a serious illness. “Let’s say Grandpa is in the hospital and very sick. They will consult me on how to talk to the grandchildren about what’s going on,” explains Charlton. “It’s a matter of knowing what to say to children at certain developmental stages.”

Future growth plans include an expansion of the program’s perinatal program that follows pregnant women whose baby may have a serious health problem. The women are connected with the pediatric palliative care team, which continues to provide them with support after the birth. With help from a donation, UHS is hiring a physician and program coordinator to build out that program.

University Hospital’s long-standing palliative care team and its program have flourished over time, says Eddy. “We’ve grown due to a lot of different engines: patient demand, physician demand, leadership awareness of the benefit of palliative care, and the passion of those of us on the team.”

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everyone who needs us should get us.*



INNOVATION HIGHLIGHTS

PROMOTORES PARTNERSHIP TO REACH
IMMIGRANTS AND HOMELESS

STRONG POPULATION HEALTH
ORIENTATION

DEPARTMENT OF VETERANS AFFAIRS
FELLOWSHIP

The team is composed of physicians, nurse practitioners, nurses, social workers, chaplains, and child life specialists, along with nonclinical members such as music, massage, pet and aroma therapists. The hospital's chief medical officer, Bryan Alsip, M.D., is also part of the palliative care team.

The program provides both inpatient and community-based palliative care across the continuum, through a broad network of outpatient and community health centers. In addition, palliative care is integrated into the hospital's cancer center and bridges into the pediatric home hospice services.

With a strong commitment to education, the program incorporates a broad array of learners into clinical care and team rounds. These include medical students, residents, palliative care fellows, advanced practice registered nurses/students, and social work students. Pharmacology residents and military residents also rotate with the palliative care service. The medical school maintains a palliative care medical fellowship program in partnership with the Department of Veterans Affairs. In addition, various members of the team will sit down for educational lunches and cover palliative care topics such as holistic pain management and symptom management, complex communication, palliative care health policy, and self-care wellness. Team members also go into the community to provide palliative care education in a variety of settings, including teaching primary palliative care techniques to providers in remote locations.

To bring joy into the lives of patients, the team developed its own version of a "make-a-wish" program. "We celebrate life whenever we can," explains Perez. "Whatever is most important to the patient, we try to accommodate that." For one sick young man, a big San Antonio Spurs fan, she contacted the basketball team, which sent an autographed jersey and other gifts. The team threw a Spurs party in his room for family and friends with decorations, music, and his favorite pizza. The palliative care team has put together similar events for other patients. "Giving to someone else brings us joy," Perez says. "This might be one of the last good things the patient and family can reflect on."

The palliative care team members have a strong sense of camaraderie, says Charlton. "We begin every morning with self-care, knowing we may need a positive way to start the day," she says, referring to a moment when team members share an uplifting and encouraging quotation, thought or activity. Each Friday, the chaplain uses this time to lead a spiritual discussion or meditation.

The program enjoys strong support from hospital administration as well as the medical school leadership, team members say. "The leadership of University Health System has provided us with tremendous support," says Jennifer LaCoss, MD, who directs palliative care outpatient services.

The health system's support of its community is an essential element to the team's success, she adds. "Our program is great because we work within a health system that tries to find access to care no matter where you come from or what your financial resources are," she says. "Our palliative care team is in a unique position to provide care even to people with few resources. That's a great asset to the community." •

MEDICAL UNIVERSITY OF SOUTH CAROLINA

Charleston, South Carolina

The 13-year-old boy was afraid to enter his dying father's hospital room. A nurse drew him in, explaining the medical side of what was happening to his dad, who was intubated, and social worker Mary Catherine Dubois helped the boy make a memory stone with his father's thumbprint. On the next visit, the nurses at Medical University of South Carolina asked the boy what music he liked, and he and his cousin danced to James Brown in the father's hospital room, infusing those final moments with joy. "It was really the memory stone that was the beginning of an opening to draw him in," explains Dubois.

The 709-bed academic medical center in Charleston revitalized its palliative care program in 2015, designing a program that balances the nuts-and-bolts of palliative care with a culture that welcomes innovation. Hospital leaders also sought to provide leadership in training and advocacy for palliative care throughout South Carolina, and its team members hold positions with both state and national palliative care organizations.

"They gave us a lot of leeway and a lot of support," Patrick Coyne, MSN, the program's director, says. "We maintain a lot of moving parts — education, patient care, advocacy and research."

The palliative care program delivers education in multiple formats. The organization has brought training in primary palliative care to more than 150 clinicians around South Carolina, and it holds nursing education courses annually at reduced cost. Additionally, end-of-life care education is available through its website and in workshops.



Along with a local hospital, adult and pediatric hospices, and the local Veterans Administration hospital, MUSC supports a physician fellowship in hospice and palliative medicine and provides future palliative providers with a wide variety of experiences such as inpatient consults, outpatient visits, and hospices in public, private, and VA settings. It also has several outpatient clinics, including one embedded in the cancer center, and plans to create an inpatient palliative care unit in the spring of 2020. Anyone can call for a palliative care consult, including nurses or a family member. "The nursing staff are our biggest advocates," says Lauren Seidenschmidt, palliative care program manager. "They know the patient very well and are able to advocate for our services."

MUSC maintains a strong pediatrics program that includes both innovative care and statewide leadership. Its pediatric providers helped found a statewide pediatric palliative and hospice care collaborative along with other academic children's health systems and Hands of Hope, a community-based program.

An important component of MUSC's pediatrics program is its advanced fetal medicine clinic. "We meet with a woman and her support system while she's still pregnant and learns her child has something very seriously wrong that may be life-limiting," Dubois says. "Whenever she comes in, when she has to make difficult decisions about the baby's health, she sees familiar faces." If the child is lost, the team follows the family through the grief process.

Additionally, MUSC's palliative care team has a vibrant and active volunteer program. Services include bereavement support, memorial services, acupuncture, reiki, massage and legacy work. One unique aspect of the program is a partnership with various legal entities in South Carolina that helps patients and families who need legal assistance but have trouble accessing legal services. Attorneys help draw up wills and power of attorney documents and provide other services that become necessary during a serious illness. Patients are fast-tracked, which is particularly helpful if they are facing legal action over delayed rent or utility payments due to their illness. "It's been a saving grace for many people," Coyne says. •



INNOVATION HIGHLIGHTS

VOLUNTEER ATTORNEYS ASSIST WITH LEGAL MATTERS

EXTENSIVE PEDIATRIC PALLIATIVE CARE PROGRAM

MULTIPLE MODALITIES FOR EDUCATION

2018 – 2019 CIRCLE OF LIFE COMMITTEE

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2009 – 2018 CIRCLE OF LIFE
AWARD WINNERS

For updates on the work of these organizations, see www.aba.org/circles-of-influence

2009

Four Seasons
Flat Rock, North Carolina

Oregon Health and Science University
Palliative Medicine and
Comfort Care Program
Portland, Oregon

Wishard Health Services
Palliative Care Program
Indianapolis, Indiana

2010

Kansas City Hospice & Palliative Care
Kansas City, Missouri

Snohomish Palliative Partnership
Everett, Washington

Department of Veterans Affairs
VA New York/New Jersey
Healthcare Network
Brooklyn, New York

2011

The Center for Hospice &
Palliative Care
Cheektowaga, New York

Gilchrist Hospice Care
Hunt Valley, Maryland

St. John Providence Health System
Detroit, Michigan

2012

Haslinger Family Pediatric Palliative
Care Center
Akron Children's Hospital
Akron, Ohio

Calvary Hospital
Bronx, New York

Sharp HealthCare
San Diego, California

2013

The Denver Hospice
Denver, Colorado

Hertzberg Palliative Care Institute
Mount Sinai Medical Center
New York, New York

UnityPoint Health
Iowa and Illinois

2014

Baylor Health Care System
Supportive and Palliative Care Services
Dallas, Texas

Lehigh Valley Health Network
Allentown, Pennsylvania

Yakima Valley Memorial Hospital
and Foundation
Yakima, Washington

2015

Care Dimensions
Danvers, Massachusetts

2016

Palliative Medicine
Bon Secours Richmond Health System
Richmond, Virginia

Cambia Palliative Care Center of
Excellence at UW Medicine
Seattle, Washington

Susquehanna Health Hospice and
Palliative Care
Williamsport, Pennsylvania

2017

Bluegrass Care Navigators
Lexington, Kentucky

Providence TrinityCare Hospice &
TrinityKids Care, Providence Little
Company of Mary Medical Center
Torrance, and Providence Institute for
Human Caring
Torrance, California

2018

Hospice of the Valley
Phoenix, Arizona

Penn Medicine
Philadelphia, Pennsylvania

Western Connecticut Health Network
Danbury, Connecticut

