2020 CIRCLE OF LIFE AWARDS

**CELEBRATING** 

# **INNOVATION**

IN PALLIATIVE AND END-OF-LIFE CARE



### **ABOUT THE AWARD**

Major sponsors of the 2020 Circle of Life Awards are the American Hospital Association, the Catholic Health Association, and the National Hospice and Palliative Care Organization and National Hospice Foundation. The 2020 awards are also funded, in part, by the Cambia Health 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.

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In health systems, community hospitals and independent nonprofit organizations, passionate leaders are transforming palliative and end-of-life care in America. Because of their work, better treatments and protocols are available for patients during this challenging time of life. More patients and family members understand their options and how to access them, and more physicians are embracing palliative care and hospice options for their patients.

This year's Circle of Life Award honorees inspire health care stakeholders to recognize that good palliative and endof-life care are simply good care: knowing what patients want and honoring their wishes. These leaders demonstrate
that patient care improves when end-of-life questions become routine questions, regardless of a person's age or
health status. They show how a single hospice can evolve to deliver a wide range of services and improve care for an
entire health system. They prove that an independent nonprofit based in a small rural town can be a national leader
in palliative and hospice care innovation. And they show how communication — the right words at the right time and
the right programming in the electronic health record — can improve patient care.

These innovative programs serve not only people with serious and life-limiting illness, but also their loved ones. In doing so, they are strengthening their communities with new knowledge, educational opportunities for caregivers and direct services that provide comfort and compassion for their patients. 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.
- Pursue quality improvement.
- · Address biomedical, psychosocial, 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 previous recipients is available at www.aha.org/circleoflife.



### **Caring Circle of Lakeland**

St. Joseph, Michigan

n the past decade, Caring Circle of Lakeland has evolved from a nonprofit hospice to a multifaceted organization that helps aging and seriously ill individuals navigate rough terrain through a wide range of services. Before 2012, the organization focused solely on caring for people in their last six months of life, says Jason Beckrow, DO, medical director of hospice and palliative medicine. "Our goal now is not six months — it's the last six years of life," he says. "How can we help folks when they come to those critical forks in the road so they are supported in whatever is best for them?"

Caring Circle includes not only hospice-at-home services, but a hospice facility, hospital- and home-based palliative care and an in-home primary care program for seriously ill patients. Its Lory's Place bereavement center staffs dozens of peer support groups on-site and throughout the area. And its Transitions program guides patients and family members in clarifying goals, accessing community resources to support those goals and arranging for assistance that is needed now or will be in the future.

That growth has come from a wide range of partnerships, including its 2012 affiliation with Lakeland Health [now Spectrum Health Lakeland, a three-hospital division of the Grand Rapids-based Spectrum Health system.]

"Once we became affiliated with the health system, we were able to transform our program from a hospice to a quality-of-life continuum," says Melinda Gruber, PhD, Caring Circle's president and Spectrum Health Lakeland's vice president of continued care services. "That's given us the opportunity to serve the large part of our community who are older adults, seriously ill or grieving."

Gruber and another Caring Circle executive serve on the health system's quality service oversight committee. "They bring perspective about how poorly health systems in America have traditionally done with end-of-life care and planning," says Kendall Troyer, the health system's vice president of organizational excellence and quality. "And

they help us think about how we can engage more proactively to provide a better end-of-life experience."

In his view, the fact that Caring Circle is a wholly owned subsidiary of the health system is essential to improving patient care. "If this were just a collaborative partnership, would we actually bring them inside to those core meetings where decisions are made — or would they be seen more as advisers?" he asks. "The tighter you can make that relationship, the better the care delivery will be designed."

The health system affiliation makes Caring Circle more financially sustainable. Because Caring Circle's palliative care program and its HouseCalls home-based primary care program for seriously ill patients demonstrate value, the health system provides financial support for both. In addition, the health system's endowment helps support its Hanson Hospice Center and Lory's Place bereavement center. "That allows us the freedom to look for ways to help other organizations in the community instead of feeling like we have to compete with them," Gruber says.

For example, Caring Circle provided funding that helped establish PACE of Southwest Michigan, a long-term care program that helps frail elderly

persons stay in their homes. Gruber and her colleagues helped design the program, hire its leaders and also serve on its board of directors. Last year, they went a step further by providing formal training in palliative care and hospice interdisciplinary care to its staff.

"By helping another organization have the capacity to do end-of-life care, we might not have those patients in our census," Gruber says. "But at the end of the day, this training leads to much better care for those PACE participants and a better experience for those caregivers who have this new knowledge."

A different type of partnership is designed to expand use of hospice — Caring Circle's original service — among

# INNOVATION HIGHLIGHTS

- / Service expansion through community partnerships
- / Training on advance care planning
- / Peer support groups for suicide loss and overdose loss



# The COVID-19 crisis also prompted Caring Circle to ramp up advance care planning in skilled nursing facilities, many of which had experienced significant outbreaks.

groups that traditionally have been wary of the specialized care. After Gruber reached out for guidance, the Strong Women of Faith Breast Cancer Support Group, which primarily serves Black women, convened a focus group in which members shared their perspectives on hospice. Members also helped design a brochure describing Caring Circle services.

"That let our community know that we were all on board with what Caring Circle is trying to accomplish for people of color," says Bertha Carson-King, the group's founder and a member of the Caring Circle board of directors. "We still fight a lot of stereotypes about this but, because of our strong partnership, we have an inroad now to a greater understanding."

As Caring Circle has matured, it has developed programming for specific audiences. For example, as deaths from suicide — the 10th leading cause of death in the U.S. — have grown, Lory's Place started a suicide loss support group that has become one of the most-attended groups, says director Stephanie Kohler. More recently, Lory's Place started an overdose loss support group in response to the opioid epidemic.

"Every grief is unique, but the needs of these groups are very unique," Kohler says.

Angie Crabtree, who recently trained as a Lory's Place facilitator with the goal of working with the overdose loss support group, knows that. When her sister Cassie died from an accidental overdose in 2014, Crabtree's family expanded to include her two nephews. "Without the tools we learned from the Lory's Place team, I don't know what we would have done after Cassie's death. We are now able to talk, smile, laugh and share memories about Cassie. Lory's Place has helped my entire family and the [staff] are simply amazing!"

Another opportunity for Caring Circle to serve the community came during a COVID-19 outbreak at a long-term care facility that was short on staff. "We were able to partner with them to provide more care for their patients who were nearing the end of life, which gave relief to their staff to focus on other patients," Gruber says.

The COVID-19 crisis also prompted Caring Circle to ramp up advance care planning in skilled nursing facilities, many of which had experienced significant outbreaks. "That gave people the opportunity to discuss whether they wanted to remain in the facility with caregivers whom they consider to be family, as opposed to going into the hospital where they would be without anyone they know," she says.

Caring Circle has trained about 40 individuals throughout the community as advance care planning facilitators, and the COVID-19 experience convinced Gruber that this must be a focus for the future. "There are a lot of opportunities to give people more access to our quality-of-life care by being very systematic about advance care planning throughout the health system and also with our community partners," she says. "We really demonstrated that we can make a difference in a facility."





### Four Seasons: The Care You Trust

Flat Rock, North Carolina

hree weeks after testing positive for COVID-19, Beulah Babich was unresponsive when she was admitted to Elizabeth House, the inpatient hospice facility operated by Four Seasons. When she woke up briefly, her nurse pushed her bed to the window so she could see her family.

Cooperative-led trial that showed, among people expected to live a year or less, discontinuing a statin to lower cholesterol levels not only did not increase mortality, but it improved patients' quality of life. And it has participated in trials that proved the efficacy of four medications that went on to receive Food and Drug Administration approval.

"You could tell how happy she was to see us all out there; she was sitting up and blowing us all kisses," her son Arthur recalled. "The staff were extremely helpful to us ... that we could witness Mom's passing without any trauma, they just granted every wish that we had."

While COVID-19 has been a daunting challenge for all health care providers, Four Seasons was well-prepared for the crisis. For the past four years, the organization has pioneered the use of in-home palliative care telehealth for its patients living in the rural mountainous areas. As the pandemic loomed, Four Seasons started moving more patients — both palliative care and hospice patients — onto its telehealth platform.

By June, 50% of rural palliative care patients were receiving care via telehealth, and Four Seasons was exploring ways to move other services, like patient navigation and private-duty nursing, to telehealth as well.

"After doing this for many years now, we know that it leads to better patient care and higher family satisfaction," says Janet Bull, MD, Four Seasons' chief medical officer. "This is the way of the future, so we're trying to lead that."

Innovation is the hallmark of Four Seasons, a nonprofit organization that serves 11 counties in western North Carolina. With about 400 employees and another 400 volunteers, the organization provides care navigation, home care, palliative care, hospice care and bereavement services. In 2005, it established a clinical research department — rare among community-based programs — and has conducted more than 40 clinical trials, primarily to support new knowledge in symptom management and interventions to improve quality of life.

For example, Four Seasons participated in a Palliative Care Research

Four Seasons also has conducted investigator-initiated studies, including one that explored the impact of using pharmacogenomics — how a patient's genome can influence his or her responses to drugs — in the hospice and palliative care setting. Researchers took cheek swabs from about 100 patients to identify their genetic makeup, which informs how they metabolize various medications.

"This allows the pharmacist to make recommendations to physicians about switching medications, changing the timing of medications and the side effects to look for," says Bull, noting that the results of the study will be published soon. "This is also the way of the future."

Four Seasons' focus on using data to inform care is reflected in its extensive work in developing and collecting quality measures. In 2003, the organization

teamed with an academic medical center to develop a set of core measures, which led to the formation of a statewide consortium for benchmarking. That effort — renamed the Global Palliative Care Quality Alliance — grew nationwide and recently joined with others

to become the Palliative Care Quality Collaborative, which is creating a national, unified palliative care registry for the industry.

INNOVATION HIGHLIGHTS

/ Palliative care delivered via in-home telehealth

/ Clinical trials to improve patient care

/ Benchmarking of quality measures

That spirit of collaboration is also seen in Four Seasons' leadership within Teleios Collaborative Network, created to strengthen and support nonprofit community hospices to make them sustainable. "It brings together like-minded organizations to help with leadership development, marketing, business development, clinical operations, compliance, and the list goes on," says Millicent Burke-Sinclair, EdD, MBA, Four Seasons' CEO.

Since its inception in 2017, the network has grown to 10 hospice and palliative care programs in five states. Among other things, Four Seasons provides leadership development training for network members and shares some employees.



### **Choices and Champions, Novant Health**

Winston-Salem, North Carolina

aving an advance directive is important, but knowing what a patient wants is essential. For the past seven years, Choices and Champions at Novant Health has made conversations about a patient's values and wishes a top priority. "Yes, we'll complete documents, but the important thing is the conversation," says Deb Love, a clinical bioethicist who led an interdisciplinary transformation team until her recent retirement.

The program name communicates a big idea: Every patient, regardless of age or health status, should identify their "champion" — a health care surrogate — and should keep that person apprised about their choices, that is, their priorities if they face a potentially life-limiting situation. And their choices and champions should be recorded in their electronic health record (EHR) so all clinicians know the patient's perspective.

Novant Health includes nearly 600 physician practices and 15 medical centers in North Carolina and Virginia. The organization operates two hospice programs, three inpatient hospice units and one residential hospice facility.

Choices and Champions grew from the inspiration of Melissa Parker, a Novant Health lawyer at the time, who recognized that advance care planning could be improved. Traditionally, the health system had focused on urging patients to complete advance directives. As with most health systems, the majority of patients did not do so; for those who did, the document was rarely available or consulted when end-of-life decisions needed to be made.

"Then you get to the issue of whether the advance directive even addresses the issue that we are trying to deal with. And a lot of times it doesn't," says Parker, who now serves as Novant Health's patient advocacy officer and vice president of patient services.

In 2013, she approached Carl Armato, the health system's new CEO, with her concern, and he challenged her to

transform end-of-life care for the entire system. The task was daunting: Palliative care was offered in only two hospitals at that time; hospice care was provided mostly via loose affiliations with other organizations; and no one was in charge.

Today, palliative care is available in 11 Novant Health hospitals, and more than 6,000 patients received palliative care in 2018, up from fewer than 2,000 in 2014. The health system's hospice programs have year-over-year growth of at least 12% since Choices and Champions started.

The improvement in services for seriously ill patients has come, in large part, by initiating conversations among people when they are healthy. "We came up with the concept of Choices and Champions because we didn't want this to smell like death," Parker says.

As part of the registration process at every primary care visit, adult patients are asked to identify the person they trust to speak on their behalf if they are unable to do so. As a result, more than 1 million patients have a documented health care surrogate. Meanwhile, inpatients are asked

about their goals of care. More than 80% of Medicare inpatients, regardless of diagnosis, have a documented advance care planning note in their EHR.

"Choices and Champions is the perfect program for any-body — all ages, young and old," says Kelli Sadler, RN, vice president of nursing and market chief nursing officer at Novant Health. She knows from first-hand experience. In her family, talking about death or dying was taboo — until her own health emergency made her realize that she had not discussed her wishes and preferences with anyone.

"My family and I have become extremely real since my heart attack. We have more real conversations now ... and that feels so much more natural than trying to hide your emotions. It has strengthened us as a family."

# INNOVATION HIGHLIGHTS

/ All adult patients identify a health care proxy

/ Goals of care documented in electronic health record

/ Program success tied to executive compensation



Because of Choices and Champions, patients are frequently asked to articulate their values and wishes, so the conversations needed when they become seriously ill are a bit easier to have. "Finally, palliative care and hospice are widely recognized as part of this whole continuum of advance care planning," says Kim Darden, senior director for hospice and palliative care services. "This has opened the door for us to be an option alongside curative, aggressive treatments as well as an option for not continuing to pursue that course."

Parker attributes the progress to a culture shift that began in 2015 when Atul Gawande's "Being Mortal" was chosen for Novant Health's system-wide book club. More than 8,500 copies of the book were distributed free to staff members, and Gawande came to Winston-Salem to discuss the importance of end-of-life planning. "That gave us a lot of credibility," she says.

The next step was embedding Choices and Champions information into existing educational programming. For example, the onboarding program for new providers includes a one-hour session about why advance care planning conversations with patients are standard practice at Novant Health. "We establish very early that this is a normal part of our process with patients," says Adam Koontz, director of bioethics and Choices and Champions.

Another key to success, in Parker's view, is linking executive compensa-

tion to Choices and Champions' success. Two goals — documenting a patient's champion and documenting goals of care for Medicare inpatients in the EHR — were tied to incentive compensation for Novant Health's top 72 leaders.

Advance care planning has evolved from ticking boxes on an advance directive form to a real conversation about a patient's goals of care. "It used to be, 'I don't want CPR, I don't want a breathing machine, I don't want to go to a nursing home,'" Koontz says. "We have shifted from what you don't want when you're dying to what you do want while you are living."

For example, family physician Larry Weems, MD, once had an older patient who was preparing for her third knee-replacement surgery, all on the same knee. When he asked about her goals of care, she said she wanted to be able to help her new husband renovate a farmhouse they had recently purchased.

That note, now embedded in her health record, communicates to all clinicians that the patient is willing to endure a lot of pain to reach her goals, says Weems, physician executive for Novant Health's Hospital-Based Medicine Institute. "Those conversations allow me to know my patients better," he says. "When we get to a point where things aren't going well, we know you and we're going to honor your wishes. That's the end point where we want to be."

### **PAST CIRCLE OF LIFE AWARD WINNERS**

### 2019

University of Colorado Palliative Care Service Aurora, Colorado

University Health System Palliative Care Team, San Antonio

Hospice of the Western Reserve Navigator Program, Cleveland

### 2018

Hospice of the Valley, Phoenix

Penn Medicine, Philadelphia

Western Connecticut Health Network Danbury, Connecticut

### 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

### 2016

Palliative Medicine Bon Secours Richmond Health System Richmond, Virginia

Cambia Palliative Care Center of Excellence at UW Medicine Seattle

Susquehanna Health Hospice and Palliative Care, Williamsport, Pennsylvania

### 2015

Care Dimensions, Danvers, Massachusetts

### 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

### 2013

The Denver Hospice, Denver

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

UnityPoint Health, Iowa and Illinois

For more information on past winners, visit www.aha.org/circleoflife.



# Nancy and Skippy Weinstein Inpatient Hospice and Palliative Care Center

Morristown Medical Center and Atlantic Health System, Morristown, New Jersey

avid Betts, a retired cancer patient in northern New Jersey, had never heard of palliative care until earlier this year, when the tumor pushing on his spinal cord started causing more pain than his medication could relieve. "Pills take too long to get to the pain," Betts says.

That's when his oncologist referred him for outpatient palliative care at Morristown (N.J.) Medical Center. Brenda Matti-Orozco, MD, chief of the medical center's general internal medicine and palliative medicine division, found the right medication and route of administration — in Betts' case, a drug pump — and she fine-tunes the dosage for optimal effect. She works with his other physicians and the visiting-nurse service to make sure pain management is coordinated with all aspects of his care.

"Dave has not missed one cancer treatment because his pain is managed well enough that he can get there, sit in the chair for a couple hours to get his treatment and make it back home," his wife Sandy says.

That's why Matti-Orozco and her colleagues are focused on extending palliative care beyond the walls of the hospital, reaching patients in outpatient and community settings.

"We really want to push palliative care more upstream," says Matti-Orozco, who also serves as medical director of the hospital's Nancy & Skippy Weinstein's Inpatient Hospice and Palliative Care Center. In addition to inpatient hospice and palliative care services, the medical center's Weinstein Center Program operates two outpatient palliative care practices — one located at its cancer center, the other embedded at a primary care practice. The health system this year will open two other palliative care outpatient clinics to serve all five hospitals.

Morristown Medical Center nurses have been at the forefront of many palliative care initiatives, including the effort in the emergency department (ED). In 2016, requests for palliative care consults were made, on average, at least eight days after hospital admission, which often meant needless suffering. "We recognized that a lot of patients who end up in the ED are coming from long-term care facilities and truly would benefit from palliative care," says Matti-Orozco.

To address the problem, a geriatric nurse practitioner, Susan Boyle, APN, worked with a palliative care nurse practitioner to train ED nurses to recognize parameters that might warrant a palliative care consult. Initially, a nursing assessment that pointed to palliative care required the ED nurse to have a conversation with a physician to discuss the possibility of a consult, which the nurse ordered and the physician countersigned. Now, the electronic health record is programmed so that a nursing assessment triggers a best-practice advisory for a palliative care consult, which the physician can request electronically.

The process has increased the palliative care consultations in the ED to an average of 35 per month as of the first quarter this year. Although technology contributes to the progress, communication training for ED nurses and physicians is even more important, says Elizabeth Bertolini, RN, clinical nurse ethicist and certified hospice and palliative care nurse at Morristown Medical Center. The training includes the use of "patient actors" to allow nurses and physicians to practice challenging conversations.

The other four Atlantic Health hospitals now are adopting the ED

protocols as a best practice in their facilities.

## / Palliative care in the emergency department

**INNOVATION** 

**HIGHLIGHTS** 

| Electronic health record support for palliative care consults

**Nurses trained in** primary palliative care

Another nurse-led innovation by Anne Cantine, RN, and Bertolini the Palliative Care Learning Collaborative — serves twin goals: improving patient care while diminishing moral distress for nurses. "In some units, it was easy to see a disconnect between aggressive measures, such as intensive care, and the concerns that nurses had about whether this was the right thing to do for a person," Bertolini says.

Through the learning collaborative, bedside nurses, social workers and others receive education that gives them competence and confidence to understand what palliative care is, how it benefits patients and how to discuss it with patients' families and all members of a multidisciplinary team. They are empowered to engage with patients who express their goals of care and to share those conversations with physicians so that treatment plans can be tailored to patients' wishes. "This is so welcomed by our nurses," says Kim Belton, APN, nurse manager of the Morristown Medical Center's palliative care and hospice center.



CIRCLE of LIFE®

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