

CIRCLE OF LIFE AWARD



2015



CIRCLE *o*f LIFE™

*Celebrating Innovation in Palliative and End-of-Life Care*

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](mailto: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.

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

## INTRODUCTION

The Circle of Life Award celebrates innovation in palliative and end-of-life care to help seriously ill patients and their families receive high-quality, coordinated, supportive care.

In the profiles of the 2015 award honorees that follow, you will find inspiration and innovative ideas to enhance your organization's efforts in palliative and end-of-life care. You can also learn from past honorees by reading the stories at [www.aha.org/circleoflife](http://www.aha.org/circleoflife).

What is the future of palliative and end-of-life care? After the profiles, nine national experts in clinical, psycho-social and spiritual disciplines, in hospitals, hospices, long-term care facilities and foundations, share their perspectives. This award serves not just to recognize the accomplishments of our honorees, but also to share their ideas and approaches with the entire health care community. We hope you find this booklet a useful starting point when considering ideas on ways to strengthen your organization's efforts.



Rich Umbdenstock  
*President and CEO*  
*American Hospital Association*



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AWARD WINNER

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CARE DIMENSIONS

*Danvers, Massachusetts*





Care Dimensions, the largest hospice in the Boston area, was providing excellent care to children occasionally needing hospice and palliative care. But to build a more robust and comprehensive program, two years ago, the hospice hired Tamara Vesel, MD, a board-certified palliative care specialist from Dana-Farber Cancer Institute and Boston Children's Hospital. To enhance the skills of hospice staff whose experience was primarily with adults, Vesel developed an intensive staff training program in the emotionally charged world of caring for dying children.

The specialized training prepared Care Dimensions staff for the day a very sick three-year-old's heart stopped during an airplane flight with his family. CPR was performed while the plane returned to Boston, where the child was rushed to the hospital. The family wanted the child's death to occur at home so they could take him to their mosque and prepare him for a traditional Muslim funeral. Vesel and a pediatric team nurse were waiting in the family's driveway when they returned from the hospital. Over the next three days, the team supported the parents in their difficult decision to remove the child's breathing tube.

"Removing advanced life support in a home setting is not something a lot of hospice programs would take on," says Nate Lamkin, the hospice social worker working with the family. "As tragic as it was, the family felt very well supported and the staff coped well with it." Building the new pediatric program has had a profound effect on the whole organization, says Lamkin, reinforcing the hospice's compassionate mission.

Care Dimensions has grown over 35 years from an all-volunteer hospice to a leader in palliative and hospice care in a region that boasts some of the nation's premier medical institutions. Its leaders take that position seriously and emphasize building bridges with a wide variety of partners, including hospitals, nursing homes, assisted living communities and physician practices. "We have tailored our care to our customers...and we do things differently depending on their preferences," explains Rob Warren, MD, medical director of palliative care. Details on those preferences are maintained in individual profiles in an online toolkit available to all staff members. "Communication is key," says COO Judy Cranney. "The primary physician, specialists as well as case managers want to be involved in all aspects of the patient's care. We provide clinical updates and status changes electronically or in the communication method preferred by each provider."

As health care delivery has begun to transform to emphasize value-based models that increase financial risk and integration throughout the continuum with the goal of managing care of patients and keeping them out of hospitals, Care Dimensions is positioned well as an important partner.

The organization became Medicare-certified in 1989 as the Hospice of the North Shore and in 2002 began a palliative care service in collaboration with Salem Hospital, continuing to grow from there.

The organization's reputation for competence in hospice and palliative care was affirmed when Boston's Partners HealthCare approached it to take over its hospice program, which it did in 2011, expanding its geographic reach significantly to Boston and eastern Massachusetts. The hospice subsequently changed its name to Care Dimensions. "There were two things our organization was known for — expertise in end-of-life care and compassion, and those two are inextricably linked," says President and CEO Diane Stringer. "There is a science as well as an art to providing the best end-of-life care."

*There is a science as well as an art to providing the best end-of-life care.*



#### INNOVATION HIGHLIGHTS

PALLIATIVE AND END-OF-LIFE CARE  
EMBEDDED IN A LARGER SYSTEM OF CARE

BROAD RANGE OF SERVICES

APPROACHES TAILORED TO THE PARTNER  
ORGANIZATION NEEDS

OUTREACH TO TRADITIONALLY  
UNDERSERVED GROUPS

The hospice board includes representatives from local hospitals and health systems to ensure communication is also taking place at the higher strategic level and to be sure the hospice is at the table in conversations about regional risk sharing arrangements, says Stringer. Care Dimensions recently signed an agreement with the Cambridge Health Alliance to provide palliative and hospice care to its accountable care organization patients. “We continue to be a strong partner with health systems as they are looking at having risk for the full continuum of care,” Stringer says. “That requires a level of sophistication around financial modeling that we are working to develop.”

“We help them keep their patients out of the ER and out of the hospital,” explains Lyn Skarmees, vice president of provider relations. “We tell them, if you let us help with symptom management, there’s a good chance this patient with congestive heart failure won’t bounce in and out of the hospital.”

Care Dimensions provides sophisticated hospice and palliative care throughout its region, including:

- Specialized clinical programs in cardiac, respiratory, dementia and pediatric palliative care designed to monitor and control symptoms so patients stay out of acute care.
- Early access that allows patients to have curative and palliative care at the same time.
- Culturally sensitive care with education for staff and volunteers on care of lesbian, gay, bisexual and transgender patients.
- Outreach with the developmentally disabled in group homes to offer support to patients and the other residents affected by their illness.
- A comprehensive palliative care service to provide pain and symptom management and goals of care conversations to patients in hospitals, skilled nursing facilities and at home.
- An extensive hospice and palliative care education program, offering more than 45 continued education courses for nurses, social workers, case managers and aides.
- Advocacy for palliative care at the state level securing hospice as a covered benefit, among other policy issues.

The hospice also maintains a robust bereavement program open to the families of those they care for and the rest of the community. This includes a wide variety of support groups specialized to type of loss, as well as a grief workshop focused on cooking and another on writing.

Care Dimensions continues to build partnerships as the health care system evolves, with high-quality care near the end of life an essential element. “We’re continually looking for ways to expand the scope and depth of palliative care and hospice services in the community,” says Stringer. •

## HOSPICE OF FREDERICK COUNTY

*Frederick, Maryland*

**F**riends and family members of hospice patients often choose to later volunteer for hospice. But this volunteer request was a little bit different — it was from the son of a man who had died in Hospice of Frederick County and was, like his parents, deaf. Hospice leaders realized it was a wonderful opportunity to build a connection with the deaf community of the town, which is home to the Maryland School for the Deaf. So the hospice hosted a two-day training session with sign language interpretation and now has a small cadre of volunteers ready to assist deaf patients and families.

The hospice's interest in reaching out to its community is one reason it has steadily grown since its establishment in 1979, when the rural area's first oncologist wanted to bring end-of-life services to Frederick County. The initial hospice was all volunteer, providing psychosocial support to patients being cared for by home health agencies.

Today, the hospice has grown to provide a broad set of hospice and palliative care services across the care continuum as part of Frederick Regional Health System. It provides pain and palliative care services at home, in 300-bed Frederick Memorial Hospital, in long-term care facilities and at its residential Kline Hospice House. Many referrals start at the hospital, and patients are followed by the same group of physicians, nurse practitioners, social workers and chaplains wherever they go in the community.

"If we see a need we identify and pursue it," says Executive Director Laurel Cucchi. "If it's around death or



dying or grief, it fits within our process. It's our responsibility to do something about it, and we have the expertise."

In 2010, the organization expanded its palliative care program with the hire of Eric Bush, MD, a physician board certified in internal medicine and hospice and palliative medicine. As medical director, Bush was given the opportunity to extend the reach of palliative care. "I applied for credentials at all the local nursing homes, and it grew from there," Bush says. The hospice now provides primary palliative care at these long-term care sites in addition to traditional hospice care and also staffs an outpatient palliative clinic at Frederick Memorial Hospital.

Strong community partnerships are a hallmark of the organization. The hospice partners with the religious community, hosting representatives of churches, temples and mosques to learn about the delivery of hospice care. They, in turn, train others within their communities to further broaden the message. The hospice works with Way Station, an innovative non-profit that provides a medical home to people with behavioral health needs and provides

palliative care services to them. It also partners with a program called Planting Hope that provides medical care and resources for the underserved and is part of regular coalition meetings with the local health department.

The hospice works with funeral homes to help families understand how they work and helped the local school system start its first crisis team.

Hospice of Frederick County has a cadre of 120 volunteers, who provide 15 percent of service hours for the organization as a whole. A growing chaplaincy program is led by Father Pothin Ngyele, who developed a spiritual assessment tool that patients can use to identify their spiritual and emotional status and needs.

Bush believes that the hospice has grown and thrived because its leaders listen to patients and families and respond to what the community needs. "The main thing I've learned is to listen to my patients and my families," Bush says. "You need to take the time to listen...if you want to make the program better."



### INNOVATION HIGHLIGHTS

**COMMUNITY PARTNERSHIPS  
AND INTEGRATION**

**CARE CONTINUITY**

**OUTREACH TO TRADITIONALLY  
UNDERSERVED GROUPS**

**COLLABORATIVE PROGRAM WITH  
BEHAVIORAL HEALTH AND  
ADDICTION MEDICINE SERVICES**



## ROLE OF PALLIATIVE CARE IN EMERGING HEALTH DELIVERY SYSTEMS

Palliative care has demonstrated the ability to improve the care of the seriously ill by reducing symptom distress, enhancing quality of life, decreasing spiritual distress and lowering costs while improving family satisfaction and adjustment to loss. However, palliative care's most significant contribution might be its exemplary role as health reform change agent. In this role, palliative care has shown the health care field:

- *Whom to focus on* — patient and family
- *Where to focus* — on communication, relationship and value
- *How to focus* — in partnership with the care recipient, their family, providers and the community.

In addition, palliative care is modifying culture by changing the dialogue to emphasize “living until you die,” aligning service delivery around personal health care preferences, seeking innovation in the use of technology (e.g., employing video conferencing to make patient visits) and human resources (e.g., employing community health outreach workers to provide in home care) and modeling population health.

Emerging health delivery models like accountable care organizations and primary care medical homes are introducing palliative care at the point of diagnosis of a life-limiting disease and increasingly incorporating it into community-based care. As an overlay to existing curative care, palliative care will eventually be a ubiquitous benefit and a fundamental part of the integrated holistic fabric of health care delivery across all settings of care. Palliative care will lead the discussion to ensure that evolving delivery systems and support best reflect the experience and aspirations of all the people served by health care.

*Stephen G. Franey • President • Franey & Associates Consulting, Inc. • Portland, Oregon*



## EMERGING MODELS OF PALLIATIVE CARE

Hospital-based palliative care has expanded significantly in the US during the past several years, and its value is amply demonstrated by the accumulating evidence of positive patient outcomes. Accessing palliative support early in the course of illness remains an area of need; waiting for a hospitalization to trigger discussions of goals of care and exploration of care preferences likely leads to unnecessary suffering. Intervening earlier in the care for patients with chronic and advanced illnesses can significantly reduce the burden of illness and improve quality of life and prognosis while at the same time reducing overall health care expenditures, by aligning expense with meaningful care.

Increasingly, community-based palliative care models are emerging that identify and initiate supportive care to high-risk individuals in the home setting, with or without a preceding hospitalization. The palliative care interdisciplinary team supports patients and their families within and across sites of care delivery — including skilled care, assisted living and private residences. As health systems seek community partners to provide a consistent dependable continuum of holistic support for patients and their caregivers, organizations or medical practices that provide home-based primary and specialty palliative care will increasingly be in demand. Health systems will look to them to assist patients and their families with care coordination, transportation, private duty help, intermittent skilled home health care or services like radiology or home podiatry, as well as quality community-based 24/7 hospice for end-of-life care.

As home-based palliative care is increasingly recognized as integral to high quality health care, the keys to effectiveness will be coordinated systems of care, optimal communication and collaboration.

*Martha L. Twaddle, MD, FACP, FAAHPM • Chair, Circle of Life Committee • Senior Vice President of Medical Excellence and Innovation • JourneyCare • Barrington, Illinois*





## PALLIATIVE CARE AND LONG TERM CARE AND DEMENTIA

**C**linical relationships between nursing homes and hospices have long provided excellent support for residents and their families at the end of life. Long term care providers are beginning now to focus on the needs of those who do not meet the Medicare hospice designation.

As the scope of palliative care has grown, so has its potential value for those receiving care in nursing homes and other long term care settings. For people with advanced chronic illnesses, including dementia, there is no question that effective pain and symptom management can make a marked difference in quality of life. The importance of palliative care does not stop there, as its fundamental purpose is to provide comfort. People with advanced dementia are not fully able to tell us how they feel and what they want, so progressive long term care organizations are developing ways of assessing pain and symptoms and ensuring that people find the comfort they deserve. As our society seeks to better provide compassionate and patient-centered care for these patients, a new and exciting frontier is opening for the field of palliative care.

*Mark Kator • Chief Executive Officer • Isabella Geriatric Center, Inc. • New York, New York*



## PAYER-PROVIDER COLLABORATIONS

**A**lthough multiple studies show hospice and palliative care improve quality of life for individuals with serious, life-limiting and terminal illness, the way these services have been delivered and financed has limited their use in the US. The Medicare hospice benefit, which forces a choice between curative treatment and hospice and stipulates a prognosis of six months or less, prevents many from using hospice at all and results in very short lengths of service for many others. And while hospital-based palliative care services are increasingly common, development of community-based palliative care services has been slowed by the lack of sufficient, defined funding streams.

The good news is increasingly commercial and government payers are modifying benefits to offset these barriers. Many health plans, including Aetna, Health Net, Anthem Blue Cross and others, have expanded the hospice benefit beyond six months and/or allow for at least limited concurrent (curative and hospice) care. Through the ACA, qualified pediatric patients may now receive concurrent care on Medicaid. And the Medicare Care Choices Model, now being studied in multiple pilots, allows Medicare beneficiaries to receive palliative care services from certain hospices while concurrently receiving curative care.

Payers also are joining with providers to create and support community-based palliative care in clinics and patient homes and over the phone. From Cambia Health Solutions in the Pacific Northwest to Highmark Inc. in the Northeast, payers are collaborating with providers to identify mechanisms for identifying patients who would benefit from palliative care, delivery models that efficiently address a broad spectrum of needs, payment models that align provider-payer incentives and metrics that assess impact on the quality and cost of care.

*Kathleen Kerr • Kerr & Associates • Mill Valley, California*



## FOUNDATION VIEW

**I**n 2006, the California HealthCare Foundation (CHCF) published a survey focused on Californians' attitudes on death and dying, clearly showing the persistent misalignment between peoples' wishes at end of life (to die at home with loved ones) and the reality (death in hospitals and nursing homes.) As a companion piece, CHCF decided to find the prevalence of palliative care in hospitals so people with serious illness could find options and resources — and to stimulate program development. That 2006 survey of all California hospitals became *When Compassion is the Cure* (2007 [www.chcf.org/publications/2012/02/compassion-cure-palliative-care](http://www.chcf.org/publications/2012/02/compassion-cure-palliative-care)) and was repeated in 2012. The positive results: steady growth of hospital-based palliative care in California, especially in large hospitals. New work this year — still searching for palliative care — also highlights community palliative care in *Uneven Terrain: Mapping Palliative Care Need and Supply in CA* ([www.chcf.org/publications/2015/02/palliative-care-data](http://www.chcf.org/publications/2015/02/palliative-care-data)).

What are we learning about the emerging role of palliative care? Despite the growing appreciation of the value of palliative care by payers, providers and people with serious illness, the capacity to provide palliative care seriously lags the growing demand. Workforce is key — both the preparation of palliative care specialists and developing palliative care competence in those who provide care for people with serious illness is any setting. Many quality of care problems at end of life are communication problems — it is heartening to see the groundswell of interest in improving conversations and advance care planning from many quarters and then working to build capacity to ensure people get the care they want.

*Kate O'Malley • Senior Program Officer, High-Value Care • California HealthCare Foundation • Oakland, California*



## THE FUTURE OF HOSPICE CARE

The delivery of hospice care in the US has changed and evolved since it was first introduced in the early 1970s. Since then, a myriad of demographic, regulatory and other changes have impacted what was once a grassroots effort considered outside the mainstream of health care delivery. What has remained constant, however, is the philosophy and the passion of dedicated professionals and volunteers who provide care in their communities across the country.

The future of hospice care is promising, yet we know there is much to be done. We wholeheartedly support the findings and recommendations of the Institute of Medicine's recent report that highlights the critical need for end-of-life care improvement in the United States.

In 2030, an estimated 69 million people will be over age 65, up from 35 million in 2000. This estimate alone speaks to the need to increase quality of care and the capacity of providers to meet increased demand. As a result, there is greater urgency than ever to educate the public about health care options and to make changes in national health care policy, education and payment systems.

Hospices currently provide care for about 1.5 million dying Americans and their families each year. The valuable lessons learned and the experiences of hospice professionals

and family caregivers can provide direction that will lead us to deliver the highest quality of care for all patients who at the end of life deserve the best care possible.

*John Mastrojohn, RN, MSN, MBA • Executive Vice President & Chief Operating Officer • National Hospice and Palliative Care Organization • Alexandria, Virginia*



## FUTURE DIRECTIONS FOR PALLIATIVE NURSING

Nurses are vital to ensuring safe, effective, appropriate, quality, patient-centered palliative care. With shared grounding in principles and goals of ameliorating suffering, the synergies between palliative care and nursing promote:

- Person-centered care and practices for patients and their families
- Front-line nursing engagement in care and improvement
- A relentless focus on advancing palliative nursing for patients with serious illness
- Transparency in quality review and communication of successes and challenges
- Promotion of innovative practices and models

As leaders in evidence-based and best practices, nursing pioneers and promotes professional development. Celebrating its 15th anniversary this year, the End of Life Education Consortium (ELNEC) has taught more than 20,000 nurses throughout the United States and in 82 other countries to provide training in palliative and end-of-life care, reaching more than 600,000 providers for an amazing impact on quality palliative care for patients and families. Additionally, more than 14,000 nurses have achieved specialized certification in palliative care.

As palliative care is integrated into new models of health care delivery including accountable care organizations, medical homes and risk sharing programs, nurses will continue to be key leaders in hospital, clinic, home and long-term care settings, bringing skills in managing pain and symptoms and ensuring optimal functioning, accessing community

resources, supporting family caregivers and promoting advanced care planning to ensure care that reflects patient values and preferences.

*Constance Dahlin, ANP-BC, ACHPN, FPCN, FAAN • Director of Professional Practice • Hospice and Palliative Nurses Association • Beverly, Massachusetts*



## SPIRITUAL CARE

Chaplains have traditionally been underrepresented on interdisciplinary palliative care teams and the power of their voice has not always been recognized. The result: too often spiritual needs have been neglected in clinical practice.

However, a growing evidence base is emerging, giving renewed urgency to embedding spirituality into palliative care team practice. Spirituality research on aspects of care associated with patient well-being and a deeper sense of meaning, purpose and connectedness indicates that the quality of caregiver presence is a critical therapeutic part of whole person care. Demonstration projects are teaching clinicians the “art of being present” and confirming behaviors that evoke trust, deepen the conversation, elicit patient’s hopes and fears and establish a healing connection.

Professional chaplains, by virtue of their clinical, theological and spiritual expertise, are uniquely prepared to be spiritual care mentors for their inter-professional colleagues. They draw upon the patient’s own spiritual strengths to heal suffering and facilitate team self-care to avoid compassion fatigue, moral distress and burnout.

Recent developments in spiritual care research and specialty certification signal a stronger future for chaplains in palliative care. In the past two years, national chaplaincy organizations have implemented advanced certification which has “raised the bar” for board certified chaplains choosing to specialize in care of the seriously ill. This new professionalism will undoubtedly strengthen the role of chaplains and the integration of high quality spiritual care practice on inter-professional palliative care and hospice teams.

*Tina Picchi, MA, BCC • Executive Director • Supportive Care Coalition • Hillsboro, Oregon*



## SOCIAL WORK

The role of palliative care social workers is constantly evolving. While social workers have long played key leadership roles throughout the continuum of palliative care, they are also playing lead roles in ensuring greater integration of palliative care into seamless care networks that ensure access to transportation for patient and family, social service and spiritual care support, home assessment to ensure an adequate environment to comply with medication management and discharge follow up.

In addition to conducting psychosocial assessments and coordinating patient/family conferences, social leaders are building programs that provide holistic care for the patient and family, understanding that care must include more than the physical care of the patient. For example, social workers are leading efforts in non-pharmacological approaches to treat pain and other distressing symptoms and creating new methods to foster advance care planning among adolescents with serious illnesses.

As palliative care professionals, social workers play an integral role in expanding the horizons and reach of palliative care through research to identify evidence-based practices and a focus on training the palliative care leaders of the future through postgraduate social work fellowship programs.

Increasingly, hospice and palliative care social workers are seeking certification and advance certification in hospice and palliative social work from the National Association of Social Workers and the National Hospice and Palliative Care Organization, contributing to nationally-accepted standards and criteria for excellence.

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