Welcome to the Spring Edition of NHPCO’s NewsLine

Internet Explorer Users – Please Note:
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DIVERSITY AND END-OF-LIFE CARE
Are You Serving All Those in Your Community that Need Your Services?

INSIDE
Information and Resources from NHPCO and its Diversity Advisory Council
Engaging Millennials, Too
ACOs and Alternative Payment Models
Short Takes, Member News and More...

National Hospice and Palliative Care Organization
## Diversity and End-of-Life Care

### An Introduction

The provider community has made strides to increase under-utilization of hospice and palliative care by minority populations but much remains to be done. NHPCO offers some context and members of the Diversity Advisory Council share helpful information.

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Collaboration between NHPCO and Morgan State University
This innovative collaboration, which will be launched in March, will help take information about end-of-life care and care planning to new audiences and will provide a model for other organizations to use.

Timely Conversations: Engaging Millennials, Too
Samaritan Healthcare & Hospice partnered with the local Gannett newspaper on a generation-spanning advance directive campaign in South Jersey. It was capped with a Day-of-the-Dead themed community event.

New Strategic Opportunities for Hospice
In the first article of a two-part series, NHPCO’s Sue Lyn Schramm looks at the importance of providers understanding and taking advantage of ACOs and Alternative Payment Models.

Diversity Advisory Council
Meet the dedicated members of NHPCO’s Diversity Advisory Council.
Join us as we celebrate Don Schumacher as he prepares for the next chapter of his life!

HELP US SHARE THE STORIES
of hospice.

This black tie evening will feature stories of hope. Of love. Of joy. Of living life to the fullest.

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Moments of Life

Learn more about how to purchase tickets, become a sponsor or donate an auction item by contacting Joy Nguyen at jnguyen@nationalhospicefoundation.org, 703-647-5167.
Message From Don

Just over three weeks ago, I announced that at the end of 2016 I will be retiring as president and CEO of NHPCO and our affiliated organizations. The news has spread throughout our community and to all those who have reached out to me with messages of appreciation, support and touching recollections from the past, let me say thank you.

As I’ve said – and am likely to say many times over in the months ahead – working on your behalf at NHPCO for the past 14 years, and heading up hospice and palliative care programs for more than 30 years before that, has been the most rewarding job anyone could have ever hoped for.

Together, we have accomplished so much. In recent years, we have protected the Medicare hospice benefit from repeated threats. We have successfully lobbied for increased oversight and appropriate regulatory measures. Working collaboratively, we have seen the number of patients served by hospice and palliative care organizations and the number of providers grow to reflect the increasing need for compassionate, high-quality care at life’s end. We have shared our philosophy of care with other provider sectors and communities across the globe.

Together, we have worked to create a more seamless continuum of care – critically important work that continues to this very day. We have tackled issues involving quality, compliance, education, awareness, advocacy, access and more. And we have done this as a unified provider community, speaking with one voice. For these opportunities, I will be eternally grateful.

While I will miss my job at NHPCO more than I can express, I do look forward to a new focus in my career beginning in 2017 with consulting, lecturing, and writing. And, most importantly, I will have more time to spend with my beloved family.

I hope that many of you will be able to attend April’s Management and Leadership Conference or to join me and the NHPCO team at the annual National Hospice Foundation Gala on Friday, April 22, 2016 at the Gaylord National Harbor where I’ll have the opportunity to express my deep appreciation to you all.

Warm regards,

J. Donald Schumacher, PsyD
President/CEO
AN INTRODUCTION TO

Diversity and End-of-Life Care
With that thought in mind, a look at NHPCO’s most recent edition of “Facts and Figures: Hospice Care in America” (2015) provides a snapshot of patient race and ethnicity of hospice patients for 2014. While the African American population accounts for more than 12 percent of the overall U.S. population, only 7.6 percent of those entering hospice programs across the country were African American – and it should be noted that this percentage has dropped in recent years. Those of Hispanic or Latino origin account for 7 percent of hospice patients and Asians or other Pacific Islanders account for 3 percent (this represents a slight increase in reaching these populations); multiracial individuals account for 13 percent.

The provider community has made strides to increase utilization of hospice and palliative care by minority communities, but much remains to be done as the minority populations in the U.S. are projected to increase in the years ahead.

In an article in The New York Times, “A Racial Gap in Attitudes Toward Hospice Care” (08/21/15), journalist Sarah Varney pointed out that by the year 2050, blacks and other minorities are projected to make up 42 percent of...
people aged 65 and over, up from 20 percent in 2000. “The racial divide is even more pronounced when it comes to advance care directives—legal documents meant to help families make life-or-death decisions that reflect a patient’s choices. Some 40 percent of whites aged 70 and over have such plans, compared with only 16 percent of blacks,” writes Varney.

**Healthcare Disparities**

Population-specific differences in the presence of disease, health outcomes and access to healthcare are all part of the healthcare disparities conversation. A 2002 Institute of Medicine study, “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,” found that “a consistent body of research demonstrates significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable. Research further indicates that U.S. racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services.”

In an article for Kaiser Health News, “Can healthcare be cured of racial bias?” (08/21/15), April Dembosky writes, “Even as the health of Americans has improved, the disparities in treatment and outcomes between white patients and black and Latino patients are almost as big as they were 50 years ago. A growing body of research suggests that doctors’ unconscious behavior plays a role in these statistics, and the Institute of Medicine of the National Academy of Sciences has called for more studies looking at discrimination and prejudice in health care.”

While the reasons for these disparities are numerous and frequently directly correlated to lower socioeconomic status, African Americans, for example, do not seek healthcare as often and when they do, it is often with a physician they may see only once. The healthcare system in America and its many services have made incredible strides over the years, yet much work is to be done with regard to differences in quality of care and treatment options based on ethnic background.

**NHPCO Takes Action**

NHPCO is committed to addressing issues of access to hospice and palliative care by diverse communities in the U.S. To help address disparities in end-of-life care, in 2015 NHPCO brought back its Diversity Advisory Council, made up of hospice and healthcare professionals and experts who are working to increase access and
understandings of the many benefits of hospice and palliative care. (Meet the members of the Diversity Advisory Council on page 14.)

The Diversity Advisory Council is being co-chaired by a long-standing champion and advocate for hospice access, social worker Bernice Catherine Harper, MSW, MSc.PH, LLD. She is joined by co-chair Melissa Rinehart, PhD, of Kaleidoscope Diversity Solutions, Inc. and Indiana/Purdue University at Fort Wayne.

To reflect NHPCO’s commitment to expanding access and reducing disparities in hospice and palliative care provision, the organization’s current strategic plan includes work to address this critical issue. While all diverse populations are important, there will be a focus on African Americans and Latinos in NHPCO’s efforts throughout this year.

In this edition of *NewsLine*, we will look at some issues of relevance that will help providers think about questions and challenges in serving diverse populations. We will also share some information about an innovative pilot project that is a collaboration between NHPCO and Morgan State University, one of America’s celebrated Historically Black Colleges and Universities (see article on page 21).

To begin, NHPCO would like to provide some additional context for this look at diversity by sharing some of the general information and focus group findings that were part of the organization’s original Caring Connections initiative, which received funding from the Robert Wood Johnston Foundation. (It’s worth pointing out that Caring Connections is now known as NHPCO’s CaringInfo.)

Information from NHPCO’s *African American Outreach Guide* and the *Latino Outreach Guide* offer some helpful insight. These guides are available in full-length and abbreviated format and can be downloaded free-of-charge from the Access & Outreach Resource section http://www.nhpco.org/access of NHPCO’s website.
African American Focus Group Findings

It’s also important to be aware of the history of African Americans in this country. Many African Americans remember the days of segregation, Jim Crowe laws and violence towards their people. And many African Americans are deeply distrustful of the government and the healthcare system, a distrust that is rooted in both historical and present day experiences. For example, while emancipation from slavery was achieved in 1865, many African American families are only three generations removed from slavery. And as recently as 40 years ago, African American men with syphilis were purposely left untreated and studied to determine the long-term effects of the disease; many died in excruciating pain, all unnecessarily. So when African Americans do seek care for their health, particularly at the end of life, it is little wonder that many worry that hospice is just another way to hasten death.

In May 2006, NHPCO conducted two African American end-of-life focus groups in St. Louis, Missouri. Men and women were interviewed separately. Group participants discussed their general feelings regarding end-of-life thinking, talking and planning. Participants were then asked to read and react to topics such as advance care planning, end-of-life caregiving and hospice.

Group participants were divided on their comfort level on the topic of death and dying – some seemed at ease, while others felt that it was culturally taboo to even discuss it. Older participants indicated that they talk about it more as they themselves are aging. Generally, there is a conflict between wanting to be informed medically, but being culturally bound to privacy and wanting to turn to and rely on faith first and foremost.

Most participants were unaware of the true meaning of advance care planning, using it interchangeably with end-of-life care, which they connected with life insurance and funeral planning. There was significant distrust that even if preferences are specified in writing, that the medical professional in charge would not honor them.

Here are some quotes from the focus group participants that provide insight:

“...It interests me now. There was a time when I used to kind of shy away from that, because… there’s just something about it that you just don’t want to talk about. You don’t want to hear about it. But as you get older, it comes to the forefront of your mind and so it’s like you want to go and find out things about it.”
“What I sense that you’re leading at is, a person fills out a document and then you get this document notarized or something and this goes to some agency and then when the person is ill then the hospital had the responsibility to contact this agency and see if this person has a document ready and the document says or the person says, ‘This person wants to be kept alive by all means possible,’ then the doctors are going to be bound by that document. I don’t think it’s going to happen like that.”

“I think we talk about mostly caring for each other or our loved one at the end, during the end of their life on earth other than just their dying. Blacks seem to be concerned with taking care of their people.”

Dr. Harper shares this perspective on the need to recognize death and dying and views on hospice within African American communities:

“Be aware that African Americans, like most of us, are not into death and dying; they are into life and living! As a general rule, they see death as going home, and going away from a world of discrimination and hardship. So they can’t get too excited about hospice. To them, hospice is a white middle-class movement, and not one they view as personally applicable. So we need to help them understand it and be aware of it and present it to people of color in the appropriate cultural context. Be prepared to address the underlying concerns of the patient and family who will respond with, ‘Where have you been my whole life? When I needed clothes? Or food? Now you come when I’m dying. But I’m going home. I don’t need this now.’ We need to break those barriers to healthcare and hospice for African Americans.”

**Latino Focus Group Findings**

Four focus groups with Latinos were conducted in May 2006 that were part of NHPCO’s Caring Connections initiative to inform NHPCO’s outreach and communication efforts to diverse racial and ethnic communities.

The focus groups were conducted with middle-aged Latinos who had not lost a loved-one in the recent past, and had never had a life-threatening illness or injury. Two groups were conducted in Spanish in Houston, and two were conducted in English in Los Angeles.

The following are some key findings from those focus groups that remain relevant today.

Although the majority of Latinos are unfamiliar with the concept of advance care planning, the subject resonated with the Latino community
and participants felt basic education materials would be helpful. Latinos, more than other Americans, are more likely to have planned for what will happen after death. They may have made funeral plans, purchased life insurance, or written a will. Participants discussed the importance for family members to come to consensus about the care of loved ones.

A majority of focus group participants said they personally would not want to be kept alive on life support, but were more divided about withholding life support from a loved one. Brief, descriptive resources on end-of-life topics including artificial nutrition and hydration are needed.

A better understanding of the term “caregiver” is needed within the Latino community. For many Latinos the term “caregiver” implies a professional role such as that of a nurse or home-health aid. Family caregivers may not identify themselves as such since caring for family members at home is part of their culture and tradition.

It is important to emphasize to Latinos the importance of family in hospice care. Some Latinos have not heard of hospice, and many who have do not know much about it. Some equate hospice with nursing homes. Nursing homes have negative connotations in Latino families because they go against the cultural tradition of the family providing care for the sick and elderly. It was with this focus group that the term “compassionate care” was found to be more effective than “hospice.”

Here are some quotes from the focus group participants that provide insight:

“Because we are going to die anyway. Why worry about something we have no control over. When we have no control over something it’s best to leave it alone onto itself. I believe, just take care of self, manage self well, and just move on. Focus on the positive in life.”

“If you are looking forward to death... it’s like you’re bringing it into your life. If you project it to the world, it’s going to come to you.”

“I told my family how I’d like things for me. But I don’t want to talk about it. I just said it once, that’s it. That’s the end of it. I’m not going to keep talking and talking and talking about the same thing, over and over.”
“I think that traditionally Hispanics don’t put their families in hospice. I mean if my grandmother was dying, it doesn’t matter that I have a career or a family or anything, I would be expected to go home. No matter where I was. And I would be there. And traditionally that’s always [been the case] because we are a tight knit community and family and a culture.”

Common Themes
In both populations that were part of these research efforts, there were some shared fears and values worth noting. Many said they would not want to be kept alive on life support indefinitely because of a fear of being a burden on their loved ones, but would want a few weeks to be given a chance at recovery. While most feel that advance care planning is a wise idea, concerns were expressed; some even stated that the very idea of writing your wishes down was quite strange, especially “pre-crisis.”

“We take care of our own” was a common message that participants shared. This reminds us of the importance of stressing that hospice supports caregivers; it does not replace family members or preclude them from playing a central caregiving and decision-making role.

While some participants had heard of hospice care, there was much confusion over what hospice really is. Some recognize that hospice is for when “they run out of things to do medically; they can’t do anything to cure you.” Yet many think of it as a place someone is “sent away to” when their family has “abandoned” them, and equate it to nursing homes. It is important to emphasize that hospice care is most often provided in a person’s own home. The most frequent concern was the financial aspect, and an inability to believe that Medicaid, Medicare and most private insurance companies cover hospice expenses. Some were still doubtful even after reading NHPCO handouts explaining the Hospice Medicare Benefit.

The role of spirituality and religion resonated strongly with all focus groups. Among African Americans and Latinos, faith can carry more weight than medicine. While one must always be careful about making generalizations regarding an entire minority population, many people in these communities are deeply connected to their spirituality and religious traditions. A faith community can serve as the bedrock of spiritual life, a center of social engagement, an
indispensable source of information on all topics and a critical foundation of support in times of crisis.

Building Trust

One of the most important things that any organization must do when working with a cultural community for the first time is to build trust. Gaining that trust takes time. Building trust needs to be your main goal in developing partnerships.

There are many common truths that hospice and palliative care providers are familiar with and we must build on those understandings while continuing to engage, talk, and most importantly, listen to those we aim to care for at life’s end.

For all those providers who are actively engaged with minority populations in their service areas, NHPCO and the Diversity Advisory Council extends deep appreciation for your efforts and hope that we may contribute to the vital work you are doing.

Meet NHPCO’s Diversity Advisory Council

Co-Chair
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Kaleidoscope Diversity Solutions, Inc.
Indiana/Purdue University at Fort Wayne

Co-Chair
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The Hispanic/Latino population will double in size by the year 2050. This growth will bring a new wave of chronic diseases among Latinos and other similarly underserved predominantly low income populations. Prevention and clinical management of these diseases will require long-range strategies to deliver improved access to quality health care. Despite improvement in medical therapeutics, significant differences in measures on quality of care among Latinos continue. Disparities in health care are related to race, ethnicity and socioeconomic status.

Overcoming deficits in quality of care among Latinos and other underserved groups requires improving the quantity and quality of information about the problems Latinos and other underserved groups encounter; along with a “patient – centeredness” approach (Rodriguez and Vega, 2009).

The following table describes key points of quality health care and possible contributions for disparities in health care quality. Also, the table suggests possible ways to overcome deficits in quality of care among underserved populations.
**COMPONENTS OF QUALITY HEALTH CARE ACROSS THE QUALITY CHASM:**

1. Safe  
2. Effective  
3. Patient-centered  
4. Timely  
5. Efficient  
6. Equitable

**POSSIBLE REASONS FOR DISPARITIES IN HEALTH CARE QUALITY ACCORDING TO THE INSTITUTE OF MEDICINE (IOM):**

1. Cultural and language barriers  
2. Time limitations imposed by the pressures of clinical practice  
3. Distrust for the health care establishment by many minority patients  
4. Lack of minority and bilingual physicians and other healthcare providers  
5. Conscious or subconscious biases  
6. Clinical uncertainty — provider and patient uncertainty about clinical decisions (Balsa et al., 2003)

**POSSIBLE WAYS TO OVERCOME DEFICITS IN QUALITY OF CARE AMONG LATINO AND OTHER UNDERSERVED POPULATIONS:**

1. Early disease detection  
2. Addressing health literacy issues with appropriate sources of information about health and health care  
3. Promoting personal and family healthy behaviors  
4. Improving effectiveness of disease management  
5. Ability to navigate the health care systems  
6. Bilingual staff  
7. Workforce that reflects the community diversity  
8. Increasing continuity and coordination of care

It is essential to promote a patient-centeredness approach in the healthcare system as it provides an important framework for organizing and assessing the impact of performance gaps. Patient centeredness is defined as providing care that is respectful and responsive to individual preferences, needs, and values, while ensuring that patient preferences inform clinical decisions. Therefore providers must use information from patient’s family, cultural background, health and health care behaviors, primary language, health care literacy and other factors when assessing patient needs, expectations and environments.

In using a patient-centeredness approach there may be improvement in the clinician and patient interaction and the possibility of creating new services.

**REFERENCES:**

Death is not an easy subject to discuss. As professionals in this field, that’s something we all recognize. In communicating with the people we care for, we must be sure we’re presenting things in a way that is clearly understood by each individual whether it’s the patient or family caregiver. This is why metaphors like “Starting to pack my suitcase,” “Putting on my traveling shoes,” or “Going home” resonate so well within the African American community.

While working at Visiting Nurse, I came with little knowledge about what end-of-life care looked like. Since then, I’ve learned a great deal. First, hospice, which I call comfort care, isn’t about dying but about living as fully as possible, despite life-limiting illness. I also learned that not all hospice patients are bedridden and some even rally during service.

According to Visiting Nurse Medical Director Dr. Ann Moore, “Scientific studies have shown that for certain conditions like heart or lung disease, patients who receive hospice care frequently longer and have a better quality of life than those who chose to continue a cycle of hospitalizations and rehabilitation stays. Several times a month, I saw patients actually improve after we stop medications and allow their bodies to rest. While their disease usually continues to progress to death, their deaths are frequently more comfortable with hospice partnering with them.”

Overcoming Myths

Myths about end-of-life care deter patients and their families from entering service. I want to share some of the common myths that
frequently come up among those not familiar with the compassionate, high-quality care we provide. While these concepts are familiar to those in the field, we should never assume that the people we care for are familiar as we are; being equipped with some clear explanations of common myths can be helpful.

**Myth: Hospice/Comfort care is only for the final days of life.**

Hospice – or comfort care – is ideally suited to care for patients and family caregivers during the final months of life. We must be able to explain that there must be a physician’s prognosis of six months or less, however, hospice patients often live past this time-frame. The Medicare hospice benefit is not limited to six months as long as the patient continues to meet the required prognosis. If a person is no longer appropriate for hospice, a referral to palliative care is called for. Some hospice patients are bedridden and others are moderately active. Every patient is different.

**Myth: Hospice/Comfort care means giving up hope and forgoing all medical treatment.**

Comfort care provides pain management, symptom control, psychosocial support, and spiritual care to patients. Hospice care is about living as fully as possible despite the prognosis. Under the Medicare hospice benefit, a curative path is not part of the care plan, it does not mean a person is giving up hope or medical care. Hospice nurses and physicians are experts in the latest medications and devices for pain and symptom relief. They’re thoroughly committed to providing comfort care in the most dignified manner possible. Visiting Nurse Medical Director, Dr. Ann Moore, puts it this way. “Hospice is not about giving up, it’s about recognizing a condition has reached a point where there are not many good options left to treat or cure it. Hospice patients can still receive medications for their long term health conditions like diabetes and heart disease and be treated with antibiotics for infections. They can also have physical and occupational therapy in certain circumstances. Hospice changes the focus of care from treatment of a disease to treatment of a person with a disease.”

**Myth: Palliative and hospice care are the same.**

Palliative care utilizes an interdisciplinary team approach like hospice care, however, patients are still receiving curative treatments from their physicians.

**Myth: Hospice means strangers care for you.**

Comfort care provides a dedicated team of specialists including physicians, nurses, social workers, counselors, allied therapists, grief professionals and chaplains. This skilled team approach emphasizes holistic care for patients and their families. They’re not there to replace family caregivers and faith leaders, but to support them. According to Dr. Moore, “Many illnesses cause significant discomfort with things like pain or nausea or anxiety. And, there are medications available to treat these symptoms; however, medications are just one treatment option available to patients. Things like massage therapy, music therapy, physical therapy and spiritual and social counseling are available to help people feel better.”

**Myth: Hospice care isn’t affordable.**

Comfort care is fully covered by Medicare, Medicaid, and most private insurance plans and HMOs. Plus, most hospice care providers will not turn away any patient for their inability to pay.

**Myth: Hospice care means leaving home.**

Comfort care services are provided in a patient’s own home, a nursing home, a long-term care facility, or a hospice care facility. In 2014, just over 93 percent of care was at the Routine Home Care level. Typically, those who come to a hospice facility do so
because they require a higher level of care that only a facility can provide. One in five patients utilizing Visiting Nurse services in 2014 came to our hospice home.

**Myth: Faith support is left to the family.**

Dr. Moore recognizes that “Spirituality is a component of every person, no matter what their specific beliefs are and hospice weaves these beliefs into the patient’s plan of care. It’s not uncommon for patients with life threatening disease to be praying for a miracle. If it’s someone’s turn for a miracle, it will happen with or without hospice care and I know that with hospice care the journey to the miracle or death is more comfortable. We see miracles all the time in hospice care, but sometimes it’s not the one people were hoping for.” Comfort care takes one’s spirituality into account as chaplains are there to support patients and families, but only if they elect these services. Oftentimes, hospice chaplains work alongside a patient’s faith leader.

Song and prayer are powerful tools to connect with patients and their families cross-culturally. Visiting Nurse Chaplain Carolyn Sherrill uses “music when ministering to patients because music is universal and has the ability to create a common bond. It relieves anxiety, brings a smile or burst of laughter and even strength to feeble hands while lifted in praise to the Lord. It brings joy into the hearts of family members when they hear their loved one join in singing an old hymn from days gone by.” Carolyn appreciates the opportunity to learn and share a variety of genres of music including Christian Gospel, Burmese, American Classical music, and more.

**Myth: Advance planning is mandatory.**

While advance planning is not mandatory, it’s highly recommended. Any medical decisions a patient or their families make in advance will be honored during the dying process. Living wills and advance directives enable patients and their families to maintain control over their care.

Aging and In Home Services Advance Care Planning Coordinator, Katie Hougham, describes it as a “process of reflection, understanding, and discussion regarding your healthcare wishes with your loved ones. The completion of an advance care planning document is a way to have these discussions when you are unable to speak for yourself… you continue to have a voice in your healthcare regardless of your current condition. The advance care planning discussion and document is an incredible gift for your family who can know that the decisions they are making are what their loved one wanted, without increased fear, guilt, or anxiety.”
Myth: Comfort care ends when someone dies.

Many people do not realize that hospice organizations offer bereavement services for those struggling with the loss of a loved one. Reactions to losing someone you love are unique and grief may affect various aspects of your life. At Visiting Nurse, we have a team of three counselors who meet with clients one-on-one and in support groups throughout the city. They are there for clients to talk to or just listen. They also offer grief and loss education programs, memorial services, retreats, and lend their expertise to area organizations. Providing interactive grief support and education serves as an integral part in honoring life, wellness, and the ability to adapt to change. All bereavement services are at no cost and are open to anyone in our service area whether they lost a loved one at Visiting Nurse or not.

Final Thoughts

The nation's hospices serve more than 1.6 million people along with their family members every year. While the majority of those served are White/Caucasian (76 percent in 2014 according to NHPCO’s Facts and Figures: Hospice Care in America) there are national efforts to educate other communities about the comfort provided by hospice care.

Visiting Nurse recently participated in a study with Dr. Kimberly Johnson at Duke University regarding access to hospice care for older African Americans. Numerous studies have demonstrated the benefits of comfort care. For example, patients receiving care at home are more likely to report successful symptom management than those in a medical facility. They also experience less depression and anxiety while reporting a greater sense of dignity during end-of-life. This is why there are nationwide efforts to break down barriers for minority access to comfort care.

Everyone deserves to receive the best care possible nearing the end-of-life. Hospice is integrative and designed to address all aspects of health and well-being – physical, mental, social, and spiritual. No one needs to pack their suitcase without these core elements being looked after. No one needs to go home alone.
Collaboration between NHPCO and Morgan State University

NHPCO’s strategic plan includes expanding hospice and palliative care access to diverse communities where a disparity of care exists. A unique collaboration between NHPCO and Morgan State University will help to move this important initiative forward and take essential information about end-of-life care to audiences that might not be familiar with the services that hospice and palliative care provide.

NHPCO and MSU will offer the following courses focused on educating caregivers to make informed decisions about end-of-life care. NHPCO is working with Morgan’s Center for Continuing and Professional Studies which provides professional development courses and career training programs to diverse populations throughout the Baltimore metropolitan area, the state of Maryland, and neighboring communities. While these courses will not offer academic credit in the traditional sense, the education and awareness gained should be valuable to course participants.

“We will start this important work with Morgan State University, but the overall plan is to equip local hospices around the country with a model for working with Historically Black Colleges and Universities in their areas to address this disparity of care,” says President and CEO J. Donald Schumacher. “The new partnership with Morgan State University will allow us to reach African American families in new and different ways.”

NHPCO shares information about each course and introduces our esteemed faculty.

**Spirituality and Hope at the End of Life**

**Pastor Corey L. Kennard, MACM**

People who are very ill often ask spiritual questions, in seeking comfort, meaning and hope. While clergy, chaplains and other spiritual leaders may play an important role in spiritual care, family and friends can offer important spiritual support too. This course will help participants better understand the intersection of faith and hospice care, explore questions that will help participants understand spirituality when facing life-changing situations and learn how to ensure spiritual beliefs are respected when making decisions about your healthcare. *Spirituality and Hope at the End of Life* will be the first course offered on March 24 as part of this innovative program.

Corey L. Kennard is founder and Pastor of Amplify Christian Church, a Christian teaching fellowship, and the Amplify Christian Institute of Spiritual Development in Detroit, Michigan. He
also serves as Manager of Spiritual Care for the St. John Hospital and Medical Center.

**What is Hospice and Palliative Care?**

Geoffrey Coleman, MD, MHA
Jennifer Kennedy, RN, MA, BSN, CHC

Understanding hospice and palliative care is something NHPCO’s membership knows quite well, however, attendees of this and other sessions that will be offered as part of this program may not. Faculty will explain the care, comfort and support that hospice and palliative care bring, both to patients and families. This course will dispel some of the myths surrounding hospice and palliative care, help participants understand payment sources, and provide resources to help patients and family caregivers choose the right care at the right time.

Geoffrey Coleman has been a hospice physician since 2003, mostly in the Tidewater area of eastern Virginia. Earlier in his career, Dr. Coleman delivered medical care in Nairobi, Kenya and at a Native American Tribal Clinic in Wisconsin. Dr. Coleman earned his M.D. at Temple University and is certified in Hospice and Palliative Care Medicine, as well as in Family Medicine.

Jennifer Kennedy is NHPCO’s Director of Regulatory and Compliance and educates hospice providers all over the U.S. She has close to 30 years of experience as a leader and nurse in diverse healthcare settings and has worked in hospice and palliative care for more than 17 years. She is working on a doctoral degree in health care education and policy.

**How to Plan and Communicate Your Future Healthcare Wishes**

Gloria Ramsey, JD, RN, FAAN
Cozzie King

This session will help participants answer the critically important question, “Who will speak for you when you can’t speak for yourself?” Our faculty will explain components of advance care planning and what it means to make your wishes known. Advance care planning decisions are not made lightly and participants will learn how to initiate what can be challenging discussions with loved ones and other care providers. Tools and resources will be offered.

Gloria Ramsey is well known for her work in bioethics, research ethics, nursing education, and practice. She holds a bachelor’s degree in nursing from Jersey City State College and a JD from Seton Hall University School of Law. Dr. Ramsey’s research has focused on end-of-life issues, nursing ethics, health disparities, and community health.

Cozzie King manages access related programs at NHPCO that ensure patients and families are aware of and have access to quality hospice and palliative care services and serves as staff liaison of the Diversity Advisory Council. As a member of the American Society on Aging, she participates in the Network on Multicultural Aging Committee and the Student and Emerging Professionals Group.

**Loss, Grief and Bereavement**

Barbara L. Bouton, MA, FT
Lisa Harvin, MSW

Loss, grief and bereavement are universal experiences yet each person’s reactions are unique and personal. Loss and grief following death is expected, and is also experienced in response to changes that occur with illness, divorce, loss of a job and other significant “shifts” in our lives. This course will offer an understanding of the loss, grief and bereavement experience.
This course will dispel some of the myths surrounding hospice and palliative care.

Barbara Bouton oversees and coordinates professional development and continuing education/continuing medical education at NHPCO. She holds a Master of Arts from the University of Louisville, a Fellow in Thanatology through the Association of Death Education and Counseling, and has over 26 years of experience in hospice care, grief and bereavement, and education.

Lisa Harvin serves as the Bereavement Support and Outreach Coordinator in the Gilchrist Grief Services department, a comprehensive program of support, education and counseling for those who are grieving. Additionally, Lisa provides outreach and education to city faith communities, funeral homes, agencies and organizations by conducting presentations, training and workshops on grief and loss.

SESSIONS OF INTEREST AT MLC 2016

For participants at NHPCO’s 31st Management and Leadership Conference, Leading Through The Currents of Change, April 21-23, 2016, a number of relevant sessions on access and inclusion will be offered. Here’s a rundown of those session:

**THURSDAY, APRIL 21, 2016**

**Faith and Hospice: Partnering with African American Churches to Increase Awareness of Hospice Services** (session 4C, 2:45 pm – 3:45 pm). Faculty: Apollo Townsend Stevens, DNP, RN.

**Reaching Out and Serving the Latino Community** (session 5C, 4:00 pm – 5:00 pm). Faculty: Patti Anewalt, PhD, LPC, FT, CRC and Deborah Gonzalez, MSW.

**Meet the Diversity Advisory Council:** During the Opening Welcome Reception (6:00 pm – 6:30 pm), gather at the NCHPP Meet Up Lounge (booth #203 in the exhibit hall).

**FRIDAY, APRIL 22, 2016**

**Turning Crisis Into Opportunity** (session 8A, 2:15 pm - 3:15 pm). Faculty: Gil Brown, MS.

**Meet Me at the River: Resistance, Spirituality and Inclusion of African Americans** (session 8C, 2:15 pm - 3:15 pm). Faculty: Jessica Talley, LCSW-C and C. Brandon Brewer, MDiv, CEOLS.

**SATURDAY, APRIL 23, 2016**

**Access to Hospice and Palliative Care Services: A Model Program for Professional Organizations** (session 11C, 10:00 am – 11:00 am). Faculty: Diversity Advisory Council members.
Diversity Resources Available from NHPCO

As part of the outreach and access tools that NHPCO makes available, we have some resources to help members reach out to diverse communities that can be found on a new web page for providers. NHPCO’s Diversity Initiative seeks to increase access to hospice and palliative care services within diverse communities, especially African Americans, Latinos and other communities of color.

Visit [www.nhpc0.org/diversity](http://www.nhpc0.org/diversity) to learn more about the Diversity Initiative, access materials, learn about upcoming educational programs, discover networking opportunities and more.

Support NHPCO’s Diversity Initiative

NHPCO believes that everyone should be able to easily access hospice and palliative care—that race, religion, culture, personal beliefs, language, age, financial means, and other personal characteristics should not hinder access to care. The work we are doing is crucially important but it comes at a price. If you agree that all people should have access to this great care, show your support with a financial gift through the National Hospice Foundation. [Donate today.](http://www.nhpc0.org/diversity)

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For more information, please visit: www.nhpco.org/marketplace or call (800) 646-6460
TIMELY CONVERSATIONS: ENGAGING MILLENNIALS, TOO

By Carol Paprocki
Director of Communications
Samaritan Healthcare & Hospice
A hash-tagged Day-of-the-Dead party capped an innovative, generation-spanning advance directive campaign for a South Jersey hospice and its local Gannett newspaper.

It was a party with a purpose delivered via an edgy Day-of-the-Dead theme.

More than 150 guests, vendors, staff, and volunteers braved sporadic downpours for the promise of free food, beverage, live entertainment – and the chance to engage in death-centric activities and conversations on topics often left unspoken. The Day of the Dead – a traditional Mexican cultural holiday celebrating the memories of loved ones through art, cooking, music and family activities – provided a great frame of reference.

The arts-driven, activity-rich, interactive evening, titled #BeforeIDie, was part of a long-term project between Samaritan Healthcare & Hospice, southern New Jersey’s oldest hospice, and the Courier-Post, a Gannett publication serving South Jersey.

The collaborative project aimed to encourage everyone – but particularly millennials – to join a community conversation about what matters most to them when it comes to end-of-life wishes. The goal: To shift the national conversation about death and dying to one of more acceptance, planning, and control of long-term wishes and care options, including palliative and hospice care.

The event program set the tone: “Death-positive experiences are part of a coast-to-coast movement – and we thank you for joining us in bringing the movement to Collingswood (NJ)…. The Twitterverse is alive with talk of death, and hashtags like #BeforeIDie that inspire us to confide bucket lists and heartfelt wishes, with an eye to the reality that our time is finite. Once we fully grasp that fact, it can empower us to grasp the importance of each day we are
given, and to make the most of our journey. And that makes tonight’s party very much about Life until Death! So eat, drink, talk, and share! Then carry the message to all you know and care about!”

Andrea Monzo, 33, arrived with mixed feelings. She wasn’t sure she wanted to tackle this subject, but was curious enough to come to the party held at Perkins Center for the Arts. Afterwards, she said, “It’s a good idea for people to think and talk about these things and be prepared. I wanted to see what approach they used. Bringing awareness in a fun way – with food, art, drinks – who doesn’t like that?”

A female college student came at the suggestion of her professor to gain insight and content for her final project in a Public Speaking elective course. (She reported back to Samaritan staff that her speech to her millennial classmates earned her an A).

To the surprise of the planning committee, the event also attracted many non-millennials. Support for the journey had drawn a middle-aged couple to attend. The slight woman, whose buzz-cut-length hair hinted at her ongoing battle with cancer, shared that her brain tumor was not responding well to her latest chemo regimen. With her husband, she joined a group of strangers seated at a table to engage in a facilitated discussion about end-of-life considerations. At 9 p.m., the couple rose to head home for her next chemo pill, grateful for the meaningful conversation, and the resource sheet of books, websites, games, and advance directive tools.

Armed with dozens of conversation starters, the event facilitator kept the discussion fluid to accommodate guests who came and went to visit other tables and activities throughout the evening.

“What do you think about most when you consider getting older?”

“Pick the one that matters most to you: To be free from pain, to be mentally aware, to not be a burden. Why did you choose that?”

Addressing a National Need

Like many hospices, Samaritan Healthcare & Hospice had participated for years in National Healthcare Decisions Day activities designed to “inspire, educate, and empower the public and providers” about the importance of advance care planning.

“But one day a year is not nearly enough to fully engage our community in the many benefits of having meaningful conversations about what our wishes would be if we were unable to speak for ourselves,” said Joanne Rosen, Samaritan VP, Marketing and Public Affairs.

Research nationally, and in New Jersey, bears out how much remains to be done. According to the first national survey on end-of-life conversations conducted by The Conversation Project in 2013, nine in 10 Americans think it’s important to talk about their own and loved ones’ wishes for end-of-life care,
yet fewer than three in 10 have engaged in these discussions.

Similarly, a 2014 “Health Matters” poll conducted by the New Jersey Health Care Quality Institute and the Monmouth University Polling Institute, reports that more than 54 percent of New Jersey residents have no legal documents expressing their wishes for end-of-life care, and 38 percent have never talked about advanced care planning.

Building Community — and Media — Awareness

These data prompted Samaritan to launch a Timely Conversations project in 2014-15 intended to break down this “conversation disconnect.” A multi-pronged awareness campaign was devised that included:

• discussion forums in faith-based, community, school, and workplace settings
• news print, online, and billboard ads tackling conversation taboos with bold, stark headlines followed by the call to “Start the conversation.” (See Samaritan ad on page 31)
• signs on PATCO Hi-Speedline trains and platforms serving commuters traveling between southern Jersey suburbs and Philadelphia
• continuation of a semester-long elective course on hospice care at a Quaker-affiliated private high school (initiated in 2006)
• dedicated Samaritan web pages with resources to help visitors THINK about their advance care wishes, TALK about them with their family, and ACT upon them by documenting their choices in writing.

Samaritan’s public relations team “pitched” the May 2015 launch of the new ad campaign to local media, as well as healthcare and advertising trade publications, setting in motion an unexpected level of collaboration and synergy with the Courier-Post.

Paolino, the Courier’s Features Strategist and Engagement Editor, felt the topic warranted more attention to foster broad-based community awareness and increasingly important reader engagement.

So, community engagement was a strategic goal for both organizations – the hospice looking to dispel myths and educate, and the newspaper seeking to build connections with younger, digitally-focused segments of the community. Millennials, defined as those born between 1982 and 2000, fit the bill as a target audience.

Paolino had some interesting ideas to propose. But first, she had to know, “How out-of-the-box is Samaritan willing to be? Are you open to engaging millennials? Is a Day-of-the-Dead-themed party too edgy?”

Samaritan’s Rosen, in a leap of faith, answered “yes” to a millennial approach. She explained, “Though many people would say that thinking about death and dying is the farthest thing from the minds of the young, we know that people in their 20’s and 30’s are already involved in the care of their parents and grandparents, and may have already experienced significant losses. By opening the discussion to a younger audience, we hope to make these experiences a little easier.”

Priscilla Taylor-Williams, a teacher at Moorestown Friends School who facilitates Samaritan’s elective hospice course there, agrees. “Most teens I know have lost someone by the time they’re in these high school years, or they’re watching someone go through some pretty serious illness in their families. I think it’s helpful to have a way to talk about it.”

Paolino enthusiastically outlined the newspaper’s proposed commitment:

• A three-part audio podcast titled “Giving Up the Ghost” by 28-year-old reporter Mark Trible recounting his own end-of-life planning experiences

• An article series titled #BeforeIDie, that included:
  – “Before I Die: Why Everyone’s Talking,” Kim Mulford, 10/16/15
  – “Yes, It’s a Party About Death,” Tammy Paolino, 10/21/15
  – “Don’t Wait: After sudden death, survivors left to cope.” Phaedra Trethan, 10/23/15
  – “#BeforeIDie: Party with a serious message,” 10/29/15
  – “Brushes with death lead to new outlook on life,” Shannon Eblen, 12/18/15

• The October 28 #BeforeIDie party

• Five full-page broadsheet ads and one tab full-page ad to publicize the event

• A topic page on its website

• Facebook and Twitter posts (by both organizations) to create social media buzz for the project.

Gaining Community Support

Paolino set about building widespread involvement from the Collingswood community where she is a resident and active community volunteer. Collingswood – a town with a healthy downtown shopping, restaurant, and arts scene – includes many businesses owned by millennials for millennials.
Securing an event venue proved easy. Karen Chigounis, current Interim Executive Director of the Perkins Center for the Arts, enthusiastically offered to host the event, calling #BeforeIDie “groundbreaking” for her gallery and the Borough. She said, “The concept was compelling, and the fact that the Courier-Post and Samaritan wanted the arts included as a means to engage and facilitate conversation about end-of-life issues made the decision to participate easy.”

In short order, Paolino and others secured support from the borough and police department for traffic control; beverage permits, food and beverage vendors to supply tacos, empanadas, Mexican cookies, specialty coffees, craft beers and Sangria; and food trays from area supermarkets.

A large Before-I-Die chalkboard encouraged guests to add a bucket list item to the display as they entered. Samaritan supplied copies of Aging with Dignity’s advance directive tool, Five Wishes, for participants to take home and complete with family members, as well as information on hospice and palliative care.

Local singer/songwriter Sara O’Brien of Community Rocks!, a not-for-profit music-empowerment organization, recruited 11 musical performers/groups who donated their talents. Chalk artist Michael Bruce, a local business owner, agreed to help guests add their preferred epitaph to chalk-art tombstones.

Meanwhile, other committee members recruited a magician to engage in card tricks and conversation, and a face painter to create Day of the Dead designs. They amassed a variety of prizes meant to inspire conversation.

Perkins Center for the Arts recruited two local artists to interact with guests and create art on site. The center also exhibited works including a Mexican miniature altar for Day of the Dead celebrations by Philadelphia artist Cesar Viveros, a fabric sculpture created from clothing as a memorial to artist Rachel Blythe Udell’s mother, and pottery funeral urns by Alan Willoughby, David Gamber, and Karen...
Aumann. Willoughby was so moved by the event’s theme that he brought his own parents – or rather, their ashes, in a handcrafted, double urn.

**Post-Project Reflections**

Positive community response from diverse age groups maxed out the venue’s occupancy limit, and closed registration two days before the event.

Differences and similarities across age groups were noted by our conversation facilitator. The millennials had less specific answers to the questions posed. A typical response was, “OMG, I just never thought about any of this.” All age groups shared one thing in common, very few had had conversations with their loved ones or completed Five Wishes or other advance directives, which reinforces how valuable these community conversation opportunities are.

Paolino was gratified with the result of her ‘brainchild.’ She said, “As a digitally-driven Gannett newsroom, our focus at the Courier-Post is impactful journalism, community problem-solving, audience engagement, and growing a millennial/Gen-X audience. Our collaboration with Samaritan scored on all of those points. We approached this #BeforeILDie challenge with our best journalism, creating meaningful stories and a provocative podcast on many aspects of this end-of-life discussion. Our coverage, combined with our social media conversation and our extremely popular party, clearly met all of these goals.”

In late January, the Courier-Post staff learned they had won first place for their division in the Gannett Quarterly Awards of Excellence in the Consumer Engagement & Experiences Category and 2nd place for 2015 overall. The judges wrote, “The team … took an uncomfortable subject and turned it into a truly engaging multimedia project that succeeded on many impressive levels.”

Rosen said, “Our hope for millennials, and others, engaging in this very unique event was that they would open their minds and hearts to the significance of talking openly about end-of-life wishes – now while they’re healthy, rather than later, while suffering with a life-threatening illness or injury. We’re counting on them to challenge the status quo, and change things for the better!”

Both Samaritan and the Courier are open to the possibility of staging another event in 2016 to keep the community conversation going. Courier Regional Editor Jason Alt hopes that other Gannett publications will be inspired to collaborate with hospice organizations in their respective regions.

Alt’s morning-after email to his staff succinctly summarized his enthusiasm for the entire campaign,

> “Engagement. **CHECK.** Community connecting. **CHECK.** Digitally led journalism. **CHECK.** Substantive reporting about important topics. **CHECK.** Reaching out to millennials and Gen-Xers in meaningful ways. **CHECK.** Innovative. **CHECK.** Trailblazing. **CHECK.** Fun. **CHECK.**”

**Endnotes**

1. The Conversation Project National Survey 2013
LEADING THROUGH
THE CURRENTS OF CHANGE

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NEW STRATEGIC OPPORTUNITIES FOR HOSPICE:
Taking Advantage of ACOs and Alternative Payment Models
(Part One)

By Sue Lyn Schramm, MA
Director, Consulting Services, NHPCO
As the Director of NHPCO Edge, I have the opportunity to work with hospice clients around the country. Lately it seems no matter where I go, hospice leaders are worried about many of the same issues:

- Flat or declining hospice referrals
- Increased competition among hospices
- Confusion about how best to partner with ACOs and hospitals

While these issues may seem distinct, they stem from the same root causes. We are now in the midst of a period of upheaval and change affecting providers throughout the healthcare continuum. Far from affecting only hospices, these changes are altering the playing field for everyone from hospitals to physicians to the patients themselves. The good news is that for hospices prepared to move decisively there may be unprecedented opportunities worth seizing.

**Medicare: The Irresistible Force**

The force behind all this upheaval is the Medicare program, and the need to prepare for a sea change in Medicare payment structures. HHS has set a goal of tying 85 percent of traditional Medicare payments to quality or value by the end of this year. Medicare is already tying payment incentives to programs like Hospital Value Based Purchasing and the Hospital Readmissions Reductions Program, and intends to tie 50 percent of traditional Medicare payments to Alternative Payment Models (APMs) by 2018.

The squeeze to reimbursements in other parts of post-acute care contributed to the explosion in the number of hospice programs over the past decade. That’s one reason why hospices everywhere are feeling the pressure of increased competition for a patient population that is no longer growing in most parts of the country. At the same time, hospice is now more highly regulated than ever as CMS seeks to ensure that hospice remains a high quality and high value benefit under Medicare.

And yet I’m as optimistic about the potential for individual hospices to grow and expand as I’ve ever been. The reason is that I see a strategic advantage for hospice providers operating within the new world of alternative payment. Hospices have essential skills that other, larger, parts of the health care system now need.

Health systems and ACO owners are now actively looking for skilled partners in the healthcare continuum to help them achieve their financial and quality goals.
Think about it: now everyone in the healthcare continuum needs to learn how to do what hospice has been doing ever since the beginning of the Medicare Hospice Benefit. Hospice providers have learned how to manage patients that:

- Are high-need with complex, life-threatening illness,
- Out in the community in a home or home-like setting,
- Under a risk-based payment method, controlling costs of care

The World of Alternative Payment Models

Bundled payments, ACO incentives and penalties, global budget models—all are designed to put providers at risk for the cost of patient care. While hospices have been at risk from the beginning, this is new stuff for many other providers. Hospital CFOs are used to fee-for-service incentives, where the rule is “do more, get paid more.” Under risk-based payment, that gets turned on its head. The new mantra must be to give the “right care, in the right place, at the right time”.

That’s going to be a painful transition for many hospitals and health systems. We know from experience that fee for service and risk-based incentives don’t mix well. In fact they’re diametrically opposed in every way. (Does anyone else out there remember the wave of capitated payments for physician group practices back in the 1990s? And the bankruptcies that followed?)

But for those providers who succeed in making that switch sooner rather than later, tremendous benefits may accrue. They’ll be better prepared to profit from CMS’ stated goal to keep moving purchasing into value-based structures.

MACRA is the latest law that adds weight to the trend. Last April, Congress passed the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA). The primary attention at the time was to the “doc fix”, which reformed the physician fee schedule and fixes the way physicians and other healthcare professionals are paid for services to Medicare beneficiaries. But also included were provisions for new incentives for participation in alternative payment models. Those incentives will begin three years from now in 2019, with initial payment adjustments of +/- 4%. Incentives grow to +/- 9% by 2022. Note that these really are more than positive incentives; they also include downside risk that payment will be reduced if targets are not met.

The rules creating Medicare ACOs, or Accountable Care Organizations, were first developed in 2011 as required under the ACA. Program participants have come and gone as individual ACOs have found success or failure, but on balance, each year has added more participating providers and more covered lives. By the beginning of this year, CMS announced that 8.9 million Medicare beneficiaries in 49 states and the District of Columbia were covered by ACOs.

And don’t forget that a majority of ACOs actually cover commercial, or non-Medicare patients. Leavitt Partners, a firm specializing in analysis of ACOs, counted 782 ACOs by the end of 2015. Their analysts estimate that the total number of lives covered by ACOs (both Medicare and non-Medicare) could grow to as many as 100 million by 2020 given the incentives of MACRA.

January 2016 saw creation of the first Next Generation ACOs. Next-Gen ACOs in particular are required to select a network of preferred providers and connect their patients to those preferred providers. Hospices that can achieve preferred status are thus guaranteed to receive referrals from that ACO’s physicians and facilities, while hospices that are not selected may be left out in the cold.

The Implications for Hospices

Whereas formerly I heard from many hospice CEOs that they found it hard to get attention from hospital leadership, that’s no longer true in many markets. Health systems and ACO owners are now actively looking for skilled partners in the healthcare continuum to help them achieve their financial and quality goals. Hospices can be essential partners in the effort to provide the right
care in the right place at the right time, and I would add, to the right patients—the highest cost ones.

But this opportunity won’t last forever. Players are choosing panels and partners right now, and hospices cannot afford to wait to be approached. It’s an old truism, but worth repeating: If you’re not at the table, you may be on the menu. In Part Two of this article I’ll talk more about practical strategies to help hospices make sure they have that seat at the table.

What are Alternative Payment Models?

CMS is experimenting with a great variety of alternative payment schemes. As one researcher put it to me, “They’re throwing everything at the wall to see what sticks.” Medicare is still struggling to find the right mix of risk and incentives for health systems, and each program has its own implications for hospices. This list is not comprehensive—find out what models are operating in your area by going to innovation.cms.gov/initiatives/map/index.html.

- Medicare Accountable Care Organizations
  - Medicare Shared Savings Program (MSSP)
  - ACO Investment Model (for rural and underserved areas)
  - Comprehensive ESRD Care Initiative
  - Pioneer ACOs
  - Next Generation ACO Model

It’s not as important to understand the details of the individual programs as to know that with all of them, the ACO receives an incentive for the health status and costs of care for an assigned population. Note that in some parts of the country commercial- and even employer-sponsored ACOs are also key players.

- Bundled Payment Initiatives (BPCI)

These experimental programs link payments for the multiple services beneficiaries receive during an episode of care. Under the initiative, hospitals and health systems receive a flat payment for all the care required by a patient for a given episode of care. Episodes covered under these initiatives vary. For hip and knee joint replacement in the Comprehensive Care for Joint Replacement bundled payment, the hospice is included in the bundle for 90 days post joint replacement. Providers participating in these initiatives must manage costs by avoiding unnecessary expenses, like avoidable readmissions or ER visits by the patients.

■ Maryland All-Payer Model

Maryland has a unique all-payer hospital rate system that is exempted from the usual hospital DRG payment. CMS is using it to test whether making hospitals accountable for the cost of care on a per capita basis is an effective model for advancing better care, better health and reduced costs. The state of Maryland has shifted virtually all hospital payment into global payment models, giving each hospital a fixed budget that is not tied to admissions or other volume measures. While this program affects only Maryland providers right now, this could be the wave of the future for all hospitals if it works.
At the April Management and Leadership Conference, Sue Lyn Schramm, M.A. will be leading a half-day preconference session on the topic of hospice strategies for working with ACOs.

**Wednesday, April 20, 9:00am – 12:00pm**

**PC05: Taking Hospice Skills Upstream: New Ways Hospice Can Partner with Health Systems and ACO’s**

*Healthcare payment reform is creating a new set of challenges and opportunities for hospitals and health systems. This seminar will help the hospice administrator evaluate opportunities to become an active partner with hospitals, Accountable Care Organizations (ACOs) and other at-risk organizations in your market. In this session, you’ll gain clarity and a sense of direction for your organization’s strategies by learning from the perspective of three speakers: a hospice strategist, a hospice provider, and an ACO physician and owner.***

*Sue Lyn Schramm, MA, National Hospice and Palliative Care Organization, Alexandria, VA

Randall Wagner, MD, Washington Adventist Hospital, Takoma Park, MD

Robin Stawasz, LCSW, Director Innovation, CareFirst Hospice and Palliative Care, Corning, NY*

Attendees may want to consider combining attendance at this cutting-edge preconference session with the 2nd Annual Executive Business Summit, Beyond the Benefit: Delivering on the triple aim in healthcare through palliative care, happening April 20 from 5:00—6:00pm.

For more information, Click Here

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These guidelines gather the collective knowledge, expertise, experience, practice and wisdom of over 80 hospice professionals whose work takes them to the very depths of human experience. Intended to enhance applicable local, state, and federal regulations and standards, they provide information that will help hospice bereavement professionals put regulations and standards into practice, ensuring that they are including and addressing essential components of an effective hospice bereavement program.

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The Staffing Guidelines for Hospice Home Care Teams present an innovative approach to determining staffing caseloads that recognizes the wide variety of care delivery models used by hospices today. No longer "one size fits all," the guidelines utilizes an assessment process to estimate optimal staffing levels for hospice programs that includes an analysis of the model of care delivery, characteristics of the patient population served, environmental considerations, and other circumstances unique to each hospice.

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A Guide for Working Caregivers

This booklet shares insightful information about the demands of caregiving and how to deal with the daily stresses of this position.

Member Price: $1.15  Non-Member Price: $1.75

QAPI: A Step by Step Approach

UPDATED in 2014! A practical guide to planning, developing and implementing a meaningful quality assurance and performance improvement program. This workbook will prepare you with a foundation of understanding how to gather data, analyze the data, and make the "real-life" improvements that will greatly affect your outcomes.

Member Price: $189.00  Non-Member Price: $228.00

Visit www.NHPCO.org/marketplace
“Best Practices for Using Telehealth in Palliative Care” is the latest edition to the library of NHPCO’s issue briefs that address a variety of topics of relevance to community-based palliative care providers. The newest document in the growing resource series will help providers define telehealth, understand principles for implementing a telehealth program, and identify steps for implementation for various teams.

Written by Lori Bishop, RN, CHPN; Tammy Flick, RN, BS, CPEHR, CTC; and Vicki Wildman, MSN, Edu, the document has a companion PowerPoint slide presentation that can be used to help with training efforts of teams and other staff.

Members may download the companion PowerPoint, as well as all the other available Resource Series publications and PowerPoints, from the Palliative Care Resource Series page online.

Some News Links of Interest

NHPCO shares links to news articles of interest about palliative care that can be found via the members-only Palliative Care Resource section of the website. Here are some of the links shared in early 2016 that we hope members caught:

- “Is It Better to Die in America or in England?” The New York Times, 01/19/16.
- “One way America handles end-of-life care better than Canada” Vox, 01/19/16.
- “At the end of life, medicine truly becomes an art” KevinMD, 01/08/16.
- “Extra care required when dying parents have young kids” Reuters Health, 01/01/16.

MJHS Webinars

NHPCO began offering advance level training through our collaboration with the MJHS Institute for Innovation in Palliative Care. A series of webinars created for members of the Interdisciplinary team will continue throughout 2016. Each Webinar includes a 45-minute presentation lecture with slides followed by 15 minutes of interactive Q&A. Physicians, nurses, social workers and pharmacists may obtain 1.0 continuing education credits, depending on topic.

The Webinar coming up on April 7, 2016 is Futility and Goals in the Illness Trajectory: Setting Boundaries. Webinars are conducted 12:30pm to 1:30pm ET.

See the full list of available Webinars that began September 2015. Past webinars are archived online.

CSU Seminar on Community-Based Palliative Care Success

The California State University Institute for Palliative Care in collaboration with NHPCO will offer a two-day preconference workshop, “Leading the Way to Community-Based Palliative Care Success” on April 19–20 prior to the annual Management and Leadership Conference. This full-day course will arm hospice providers, health systems, aging service providers, hospitals and others with actionable tools for researching, planning, and implementing their own community-based palliative care program.
Guide to Organizational Ethics in Hospice Care

Earlier this year, NHPCO released a new resource for hospice programs and professionals being made free-of-charge for NHPCO members, the Guide to Organizational Ethics in Hospice Care.

Written by members of the Ethics Advisory Council, the Guide presents four key concepts of the hospice philosophy of care. Seven organizational values are explained and applied to seven core operational domains, with examples of how the values can be integrated into policies and practices.

The intent is for organizations and individuals to use the framework and values in this document to inform development and implementation of organizational policies, procedures, and practices consistent with ethical standards, resonant with the hospice philosophy of care.

NHPCO Members may download the Guide to Organizational Ethics in Hospice Care from the NHPCO website (log-in is required).

Now Back in Stock!

This updated “must have” manual gives you the tools to create a state of the art volunteer program. It includes competency checklists, surveys, training outlines, job descriptions and sample forms you can adapt to your program’s needs.

Get yours now!
www.nhpco.org/marketplace
Every spring, NHPCO develops new outreach materials to help members honor the volunteers in their programs during National Volunteer Week, April 10–16, 2016. (It’s one of the exclusive benefits of NHPCO membership!)

Shown here are some of the materials available in this new collection that include social media graphics and display ads. They feature the theme “Celebrating Volunteers.” The ad slicks come in assorted sizes, with and without descriptive text and are designed to coordinate with the materials that were designed for last November’s National Hospice and Palliative Care Month to help ensure consistent messaging.

Members can add their logo to these ads, or use the images or copy in other promotional materials being prepared to honor their hospice volunteers. Download these resources from the Outreach Tools page of the NHPCO website.

Don’t forget about our newly revised Hospice Volunteer Program Resource Manual available from NHPCO’s Marketplace. Released at last fall’s Clinical Team Conference in Texas, the first printing sold out in weeks. It’s back in stock and available for order from Marketplace online or by calling the NHPCO Solutions Center at 1-800-646-6460.

Have questions about compliance and volunteers? Information about volunteers and the Hospice COPs are available in the Regulatory section of the website online.

NHPCO’s E-OL has a selection of online course offerings relating to volunteerism and volunteer management. Visit E-OL for a full list of available courses on volunteering. Here are some of the most popular:

- **Beyond the Medicare Benefit: Leading Volunteer Programs the Hospice Way**
- **Complementary Therapies: Designing, Funding, Training and Integrating a Volunteer Program into your Hospice Services**
- **Dotted Lines, Curbs and Guardrails: Boundaries for Volunteers**
- **Hospice Volunteer Training: Increasing the Effectiveness of your Training Program**
Top Courses on NHPCO’s E-Online

NHPCO’s End-of-Life Online puts on-demand learning at your fingertips in a cost-effective way that keeps you up to date on issues of importance to the profession and the field.

E-OL offers robust courses addressing a wide variety of topics including: clinical, interdisciplinary, psychosocial, regulatory, pediatric, community-based palliative care, leadership and much more. Courses and webcasts are available 24/7.

Here is a list of the ten most popular offerings last year on E-OL. If you’re not familiar with E-OL, try taking one of the courses that have been popular with other professionals in the field.

1. Managing with an Eye on Finances (a Hospice MDP module)
2. Performance Measures, Quality, and QAPI: The Big Connection
3. Psychosocial, Bereavement and Spiritual Care at the End of Life: Realities, Responsibilities and Renewal
4. Comprehensive Assessment and Plan of Care
5. Inclusion and Access: The Managers Role (a Hospice MDP module)
6. Medicare Technical Reports: What They Mean for Future Hospice Payment Changes
7. Advanced Pain Management
8. Community-Based Palliative Care
9. Provision of Services - A Regulatory Module (a Hospice MDP module)
10. The Last Gasps: Relieving the Sufferings of the End-Stage COPD Patient

CE/CME credit is included in the cost (check each offering for specific continuing education approvals).

Visit www.nhpco.org/eol to view all available courses and webcasts (the “course list” link will give you an alphabetical list of all our offerings).
Hospice Buffalo Research on Dreams Featured in NY Times

Research about dreams and visions at the end of life, conducted by Dr. Christopher W. Kerr and colleagues at Hospice Buffalo, was the focus of a front-page article in the Health & Science Section of The New York Times (February 2, 2016). "A New Vision for Dreams of the Dying" by Jan Hoffman looked at the work of Dr. Kerr, a palliative care physician who researches the therapeutic role of patients’ end-of-life dreams and visions.

Under Dr. Kerr’s direction a team of clinicians and researchers at Hospice Buffalo are seeking to demystify the dreams and visions people frequently report at the end of life. These researchers want to understand the ways in which such dreams play a role in supporting “a good death” — for the patient and the bereaved.

In the NY Times article, Hoffman writes, “Those who care for the terminally ill are inclined to see end-of-life dreams as manifestations of delirium. But the Hospice Buffalo researchers say that while some study patients slipped in and out of delirium, their end-of-life dreams were not, by definition, the product of such a state. Delirious patients generally cannot engage with others or give a coherent, organized narrative. The hallucinations they are able to describe may be traumatizing, not comforting.”

In addition, Dr. Kerr was featured in an interview available on the Huffington Post (02/03/16) website, “What the Dreams of the Dying Reveal about the Human Spirit” and he delivered a TEDxBuffalo talk about his research, “I See Dead People: Dreams and Visions of the Dying.”
As a Hospice Executive Are You Looking for Critical Competitive Data to Stay Ahead of the Curve?

Look No Further… The 2015 State Hospice Profile™ contains comprehensive hospice care details for each county based on Medicare data from 2000-2013, providing the critical information needed to learn more about the competitive environment of your state.

Produced by Health Planning & Development, LLC & Summit Business Group, LLC and marketed exclusively through the NHPCO Marketplace, each 2015 State Hospice Profile™ provides vital county-level information. Full-colored charts and graphs provide information from an analysis of the last eleven years of Medicare claims data.

Here are examples of the valuable information included in the 2015 State Hospice Profile™:

- Estimated Medicare Cap usage
- Major hospice providers in the county
- Comparative hospice penetration data/market share trends
- Average Length of Stay
- Distribution of hospice census

As an added bonus, each State Hospice Profile™ also contains a National and Statewide Profile of hospice care based upon Medicare claims data going back to 2000.

State Hospice Profiles™ are individually priced based upon the number of counties in each state. Please call 1-800-646-6460 for pricing details and to order. Profiles are available for all 50 States.

To view an example of a State Hospice Profile visit: www.nhpco.org/stateprofile
Avow Breaks Ground on Lyon Palliative Care and Hospice Center

Avow held a celebratory groundbreaking event for its newest building, The Lyon Palliative Care and Hospice Center, on the Avow campus in Naples, Florida on January 12. During the public ceremony Avow leadership, guest speakers and Avow benefactress Thelma Lyon addressed the crowd and participated in a symbolic shovel toss. Construction on the two-story, 24,000 square foot building began in January with expected completion targeted for November 2016.

New Jersey Veterans Partners Receives Award

The Mid-Atlantic Society of Association Executives, a professional society of 300 association managers from New Jersey, Delaware and Pennsylvania, bestowed its 2015 Positive Impact Award on the Hospice Veteran Partnership of New Jersey (HVPNJ) at MASAE’s annual conference last December. The award recognizes “original thinking to successfully implement a project/activity and produce a positive impact on the organization, its membership, and/or its vital communities.” The HVPNJ is managed by New Jersey Hospice and Palliative Care Organization.

Pictured are some of the 72 HVPNJ members from hospices, the VA, nursing homes and veteran service offices with the award.
Senator Coons Visits Delaware Hospice

Senator Chris Coons (D-DE), met with Delaware Hospice staff members to discuss healthcare reforms and the impact on Delawareans. Delaware Hospice President and CEO Susan Lloyd invited Senator Coons to discuss healthcare reform at the federal level. “Senator Coons’ support for healthcare initiatives at the federal level is reassuring our community that it will continue to receive the highest quality healthcare services,” commented Lloyd.

Partnership for Innovative Hospice Nurse Intern Program

Delta Care Rx, a nationally known hospice pharmaceutical provider, has partnered with North Carolina’s Four Seasons Compassion For Life in the development and implementation of an innovative 12-week “Hospice Nurse Internship Program.” The forward-looking collaboration introduces nurse graduates to the day-to-day operations of Four Seasons’ hospice care and nurse leadership case management, much in the way Delta Care Rx offers on and off-campus trainings to pharmacists.
NHPCO NewsLine | Spring 2016

Member News

Hospice Buffalo Appoints New Medical Director

The Center for Hospice & Palliative Care (Cheektowaga, NY) announces the appointment of Roslyn R. Romanowski, MD, as Attending Physician at Hospice Buffalo. With a 30-year career in medicine, she will be providing home care in Buffalo and the Southtowns, and inpatient care in the Hospice Inpatient Unit at their Mitchell Campus.

mumms Welcomes Tim Blackmon

mumms® Software, a leader in hospice and palliative care EMR, welcomed Tim Blackmon last October to the mumms Executive Team as Chief Information Officer. Blackmon shares responsibilities with Chief Technology Officer Steven Turoff as the company continues to grow. Blackmon comes to mumms with a broad 25-year software engineering career.

Leading the Way to Community-Based Palliative Care Success.

NHPCO is excited to continue our partnership with the California State University Institute for Palliative Care to offer expanded access to palliative care programming. As palliative care moves into the community, who better than your organization to provide palliative care? Leading the Way to Community-Based Palliative Care Success, a highly interactive, hands-on two-day workshop, will ensure that you and your organization know what it takes to deliver palliative care in your community.

Preconference Seminar: April 19 & 20, 9:00am–5:00pm

Share news of your organization with jradulovic@nhpco.org.
Join us on our mission to build partnerships to enhance compassionate care globally.

- **Become a partner** with a hospice and palliative care program in another country
- **Support a nurse or social worker** in Africa to receive palliative care education
- **Make a donation** to expand palliative care in developing countries

Learn more at [www.GlobalPartnersinCare.org](http://www.GlobalPartnersinCare.org) or Email [info@globalpartnersincare.org](mailto:info@globalpartnersincare.org)

**Compassion Has No Borders**

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**2016 INTERPROFESSIONAL WEBINAR SERIES IN PALLIATIVE CARE**

The MJHS Institute for Innovation in Palliative Care and NHPCO are pleased to collaborate on a Webinar series offering an array of advanced clinical topics for every member of your interdisciplinary team.

[www.mjhspalliativeinstitute.org/e-learning](http://www.mjhspalliativeinstitute.org/e-learning)
The Most Important Things
Hospice patient gets a chance to swim one more time

When ten year-old Alex Cain’s Caris Healthcare clinical team asked him what was important in his life, he told them he loved to swim and go to water parks. Realizing that time was precious, Jennifer Smith, Alex’s social worker, immediately sprang to action and applied for a National Hospice Foundation Lighthouse of Hope Fund grant. In January, Alex and his family traveled to Wilderness of the Smokies, an indoor water park in Tennessee, for a weekend of fun in the water.

NHF Gala To Raise Funds for Moments of Life: Made Possible by Hospice

The theme for the National Hospice Foundation Gala being held on Friday, April 22, 2016, is “Moments of Life” and a portion of the funds raised that evening will benefit NHPCO’s public awareness campaign launched in 2014. Although the campaign has been extremely successful, there are many people still struggling with end-of-life issues who don’t know they can access hospice care.

Spreading Hospice Awareness to Underserved Populations

An exciting new partnership between NHPCO and Morgan State University is helping further NHPCO’s strategic goal to expand hospice and palliative care access to underserved populations including African American, Latino, and other diverse communities. Initially, NHPCO and MSU will collaborate on offering non-credit courses focused on educating caregivers in diverse populations throughout the Baltimore metropolitan area, the state of Maryland, and neighboring communities, to make informed decisions about end-of-life care.
THE HAN ADVOCACY INTENSIVE
advocacy in your backyard

Join us July 18-19, 2016!

THE HAN ADVOCACY INTENSIVE
advocacy in your backyard

SAVE THE DATE: July 18-19, 2016

The HAN Advocacy Intensive is the premiere advocacy event for the hospice and palliative care community in Washington, DC. The event brings together caregivers, leaders, policymakers, and Members of Congress to affect positive change for the hospice and palliative care community.

REGISTRATION OPENS APRIL 2016:
www.hospiceactionnetwork.org/intensive

“The Advocacy Intensive gives staff a heightened understanding of politics and an appreciation that they can make a difference on a large scale. The powerful interaction between our staff and our representatives in Congress builds strong allies for our program at the federal and state level.”

John Thoma, CEO, Transitions LifeCare

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2nd Annual Executive Business Summit

BEYOND THE BENEFIT:
Delivering on the triple aim in healthcare through palliative care

Free to MLC Attendees

2nd Annual Executive Business Summit

BEYOND THE BENEFIT:
Delivering on the triple aim in healthcare through palliative care

Wednesday, April 20, 2016 | 5pm - 6:30 pm ET

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National Hospice and Palliative Care Organization
Partners Making a Difference

Global Partners in Care is proud of the work and support our U.S. partner programs provide to their international partners. Here are two stories that highlight the innovative ways partners are working together to provide education and greater access to palliative care in Africa.

Making a Difference One Bike a Time
What does a bike have to do with palliative care? VITAS Healthcare of Inland Empire, in California, knows the answer. In September 2015, three staff members traveled to Zimbabwe to visit their international partner, Nyadire Methodist Mission. During the trip they delivered much needed supplies to the mission and yes...they delivered bikes. Read more...

Making a Difference with University of Notre Dame
The Hospice Foundation, the supporting foundation of the Center for Hospice Care in Indiana, has partnered with the University of Notre Dame and Palliative Care Association of Uganda, to provide a unique learning experience for students interested in learning more about care delivery in Uganda. The partnership organizes palliative care and spiritual internships. Students travel to the country and work closely with palliative care professionals to learn and understand how care is provided in the country. Read more...

Thank you for your donations for the African Palliative Care Education Scholarship Fund!
Global Partners in Care raised over $13,000 to provide palliative care education scholarships to support nurses and social workers in Africa! Read more...

Sandy Jones-McClintic, MSW, LCSW, ACHP-SW of Hospice of Arizona made a donation to the scholarship fund at the Clinical Team Conference. Sandy is also the leader of the NCHPP Social Work group.

Have Lunch with Global Partners in Care at NHPCO’s Management and Leadership Conference!
Thursday, April 21, 12 pm – 1 pm
All conference participants are invited to a free special lunch event during MLC. Specifically, you will have an opportunity to:

- Learn how to become an international partner;
- Hear from existing partners about international efforts;
- Support palliative care education scholarships for African nurses and social workers;
- Celebrate the Global Partnership Award Winner; and
- Be inspired to help other countries develop hospice and palliative care programs!

Read more...
SAVE THE DATE!

CHALLENGES ON THE FRONT LINES:
Effective Approaches to Complex Cases

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INDIVIDUAL & TEAM LEARNING

12 HOURS CE/CME CREDIT AVAILABLE

ON DEMAND
3-MONTH AVAILABILITY*

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VIDEO LIBRARY

VIRTUAL CONFERENCE ATTENDEE

"ONE OF THE BEST CONFERENCE EXPERIENCES I'VE HAD IN YEARS. AFFORDABLE EDUCATION DELIVERED IN A TIME CONSCIOUS MANNER - BEYOND EXCELLENT!"

*SESSIONS AVAILABLE TO ALL REGISTRANTS FOR THREE MONTHS AFTER THE LIVE EVENT
Links to Some Helpful Online Resources

Quality and Regulatory
- Quality Reporting Requirements
- QAPI Resources
- Regulatory Center Home Page
- Fraud and Abuse
- Past Regulatory Alerts and Roundups
- Staffing Guidelines
- Standards of Practice
- State-specific Resources
- Survey Readiness

Outreach
- Outreach Materials
- Social Media Resources
- NHPCO’s CaringInfo

Publications
- Weekly NewsBriefs
- NewsLine
- ChiPPS E-Journal

Affiliate Publications
- Giving Matters
- Focus on Compassion

Professional Education
- Education Home Page
- Webinar Schedule
- Upcoming Conferences
- End-of-Life Online
- Pediatric Palliative Care

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