

Hospice in the Continuum

How 11 Different Hospices are Expanding Services to Reach Patients Sooner



National Hospice and Palliative Care
Organization



**An Annual
Compendium of the
Continuum Features
from NHPCO's
monthly publication,
NewsLine: March
2011 - February 2012**

A Message From Don



For a number of years, I've been speaking about the importance of creating a seamless continuum of care in this country. I'm often asked to describe what I envision, so let me share a brief definition:

With a seamless care continuum, providers work together to develop a coordinated plan that addresses physical, emotional, social, caregiving, spiritual, nutritional and other needs. In some communities one or two agencies work together to offer a range of services along the continuum, while in other communities multiple organizations work together to ensure that needs are met. In either model, conversations about when and how to transition to palliative care are explored throughout the disease trajectory.

We have a great opportunity in our field right now to be more available to patients who are dealing with life-limiting illnesses. I've always felt that when a patient is first diagnosed, some of the services that hospice has been providing for 40 years are even more important and more necessary—specifically the counseling support and the opportunity to help those we care for make more effective decisions about treatment, options and choices.

Not every hospice provider needs to offer non-hospice palliative care. However hospices are the experts in treating serious and life-limiting illnesses and, therefore, must be at the forefront of the development of a seamless continuum of care.

I'm hoping that hospices in the United States will become visible and available as the experts in the care continuum, in addition to the wonderful things they are already doing to serve patients and families at the end of life.

There are a number of programs that are already extending their reach into the communities they serve. In some cases, they are providing the care and services. In other cases, they are expanding awareness of what they offer in a strategic way that should help bring patients to hospice earlier in the course of an illness. The articles in this compendium offer some examples of work being done by providers in all corners of the country. We can learn from these forward-thinking, continuum-focused providers who are out in their communities, building a footprint for end-of-life care that is not all about “the six-month criteria.”

I feel that the decade ahead of us holds much promise—if we are all poised and ready to be part of it. I extend my appreciation to the providers featured in this publication who are sharing their work with you.

A handwritten signature in blue ink, appearing to read 'Jm'.

J. Donald Schumacher
President/CEO

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Family Hospice & Palliative Care:

Transitions Program for African Americans

While access to underserved populations is improving, African Americans still rank among the nation's most underserved groups. According to NHPCO's latest [Facts and Figures](#), just 8.9 percent of patients served in 2010 were African American even though African Americans represent 13.6 percent of the U.S. population (2010 National Census Report).

Transitions, a new program of Family Hospice and Palliative Care (FHPC), just launched in February 2011, is aiming to change that, at least in the African American neighborhoods of Pittsburgh's Greater North Side.

Working in partnership with Bidwell United Presbyterian Church and the North Side Christian Health Center, FHPC's program focuses on dispelling misconceptions about hospice and palliative care while also helping families enroll seriously ill loved ones on services to help address their suffering and provide home support.

In the following interview, Transitions coordinator, Rev. De Neice Welch, discusses the program and the impact she's seeing so far.

How did you become involved in FHPC and, now, in this new venture?

I'm the pastor of Bidwell United Presbyterian Church and first became involved in this project while a member of the FHPC board of directors. During a strategic planning process, the board discovered an opportunity to focus on the African-American community residing in Pittsburgh's North Side. After holding community stakeholder discussion groups, we were able to identify African Americans nationally as an underserved hospice population and determined that an initiative of this kind fit within FHPC's mission. The chance to serve as its program coordinator was also a natural fit within the scope of my work as a community pastor.

Please tell us about FHPC’s two partners in this initiative.

Bidwell Church was first to formally partner with FHPC on this program. We are a 300-member congregation, 90 percent of whom live within the Greater North Side. The church has deep roots in the community and is over 97 years old. The leadership of the church viewed the partnership as an extension of its work. Being able to offer quality end-of-life care to our families, neighbors, and other local churches felt like a new way to reach out to those within the confines of the church as well as our community.

The North Side Christian Health Center is a long-established community service organization in the Greater North Side which offers comprehensive health care to over 5,000 patients per year, with or without health insurance. It just recently expanded its services to include dentistry and pediatric care, and added a gerontologist to its staff to address the health needs of seniors.

How did the idea for Transitions come about?

The concept came from several ideas that converged during our community stakeholder discussions.

First, local pastors expressed the need to see congregation members at the end of life in a more centralized place. Travel also proved to be difficult for the families of these congregation members who often did not have reliable forms of transportation.

Quick Facts About Family Hospice & Palliative Care

- Founded in 1980.
- Based in Pittsburgh, PA.
- Serves nine counties in Western Pennsylvania.
- Employs 220 full- and part-time staff, and 450-plus volunteers.
- Average Daily Census: 385.
- Operates two inpatient units—a 12-bed that opened in 2007, and a 14-bed that opened in 2012.
- Among the first hospices to offer innovative programming such as complementary therapies, the Quality of Life Program, and Caregiver Training.
- Introduced the Transitions Program in 2011.



Next, our research showed that in our area of Allegheny County, only 5 percent of all hospice patients were African American, 3 percent less than the national average at that time. We suspected many could benefit from hospice care, but recognized that there were cultural, religious, and racial barriers that were prohibiting access. We also heard from leaders in the community who were willing to be supportive, particularly because they believed that FHPC’s services could provide a real benefit to the community.

Why did you select Transitions as the program name?

That too evolved from our stakeholder discussions. The common words used to describe care at the end of life are at odds with the African-American culture and belief system. To African Americans, it’s not about end-of-life care or closure, but about transition.

Had the three organizations worked together previously?

No, the Transitions program was our first opportunity to work together. The Greater North Side community was not familiar with FHPC before the launch last year.

Where is the Transitions program housed and what services are offered?

The program is housed at FHPC’s Anderson Manor on the Greater North Side, with some services also provided at Bidwell Church. While the Anderson Manor site is not new to the community, up until Transitions, residents avoided it because of the historical racial practices of the former building

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owners. Our outreach efforts have helped to change that.

In terms of services, the Transitions program offers all of the services that FHPC provides to all patients and families, we just employ more targeted outreach to break down the barriers. We have also diversified our staff to help overcome the inherent mistrust of healthcare providers. As the Transitions coordinator, my job is to speak with families considering hospice, and design and implement educational programs to promote greater understanding and increase admissions.

Have you specifically recruited volunteers for Transitions?

Yes, we now have 25 volunteers working specifically for the Transitions program. Many, but not all, are residents of the North Side and members of Bidwell Church.

We have formally trained some volunteers to help with patient care, but many help support specialized programming, such as Camp Healing Hearts for grieving children. We are now in the process of training a special group of volunteers to conduct community grief groups, which is a huge need we have discovered through our outreach.

Can you tell us about the people you're serving?

We have admitted about 25 African-American patients since January of 2011 as well as three non-African Americans. Our youngest patient was in his mid-fifties and our oldest was in her early nineties. While the majority were served in the home, some received care at FHPC's inpatient unit. Our goal, for the first four years of the program, is to serve between 60 and 65 patients.

How is the program funded?

Transitions is funded through local foundations, including grants from The Buhl Foundation, the Highmark Foundation, the McKinney Charitable Trust and The Pittsburgh Foundation. We sought support for a four-year cycle and hope to be self sufficient by establishing a patient referral stream by the end of those four years.

How are you now getting referrals?

We receive referrals from our local churches, from the North Side Christian Health Center, from doctors with established relationships with FHPC, and from the community at large. We have also formed less formal partnerships with local churches and businesses which help advertise and promote our services. These organizations include a local restaurant, a funeral home, and other children and senior service organizations located on the North Side. We are also seeing an increase in our African-American census from neighborhoods other than the North Side. Though we cannot formally count them as Transitions patients, we do know they have come to FHPC as a result of our increased outreach.

How do you integrate education about hospice and palliative care into your discussions with clients without alarming them?

It has been my experience that when speaking to families at the critical time of making a decision to access hospice care, the discussion is not alarming but comforting. Personally, it has been an empowering experience to be able to offer tangible support to families that I would not have had before the Transitions program. Offering spiritual care at the end of life is also a help because this population draws largely on its faith in times of distress. When we deliver the compassionate care we promise, it helps to spread the word about the effectiveness of hospice and palliation when it would not have been previously considered.

It has been more difficult to speak of end-of-life issues with families, community residents, pastors, and other service agencies when there is no apparent or immediate need. The fear of death is still a prohibitive factor. The faith that helps African Americans through difficult times is also the same faith that believes healing will come in the form of cure if one prays hard enough or makes a deal with God. Facing immortality before a threat to that immortality is an alarming thing. So we try to educate residents in creative ways that are more palatable. The name “Transitions” is a way of speaking of the journey towards an after-life that includes death, but is not focused on death alone. We find it to be culturally more acceptable.

It’s been widely reported that African Americans have an inherent mistrust of the healthcare system. Are there other misperceptions that you’ve discovered that surprised you?

Mistrust of the healthcare system is grounded in historical fact. The mistrust has deepened due to insurance practices, less than compassionate providers, and the lack of transparent relationships between doctors and patients. It is difficult to trust a physician to handle your death when you have not felt cared for by medical professionals during your life. When diagnosed with a life-limiting illness, African-Americans tend to take care of loved ones at home without the benefit of training, monitoring, or knowledge and understanding of the disease process, but they do so with a lot of love and compassion. Handing your loved one over to others is seen as “giving up.”

Often, we are not invited to care for loved ones facing the end of life until all other avenues have been exhausted. Misconceptions about dying, pain management, medications and its effects, and the role of doctors in the process of dying are prevalent. There is also a lack of understanding of the Medicare and Medicaid Hospice Benefits. Overall, education is desperately needed.

While still new, are you noticing a change in attitude?

There has been a change in attitude among my congregation members. Many are participating in various programs to get more information and are seeking our advice concerning the needs of their loved ones. The community at large is also becoming more familiar with what we have to offer and word is spreading by those who have benefited from Transitions. However, it is a cultural shift that takes time and a lot of effort, but is worth the work.

What have been some of the biggest challenges?

It has been difficult to gather many of the pastors on the North Side to talk about end-of-life care. We have had to approach them one at a time to help explain the program. Family issues that arise around the illness of the loved one, including who is the chosen person to make the decisions about care, are difficult to navigate. Getting people to preplan arrangements is also a challenge. Again, recognizing this initiative as a cultural shift means it will take time, so we patiently work our way into that shift. I think it is also difficult dealing with the personal grief that goes along with the work that we do.

What advice can you give to the provider interested in similar outreach?

Every aspect of hospice, palliation and end-of-life care is new to this population. It is slow to embrace the hospice option and much education is needed about what hospice care actually entails. There is a great need to have churches and other community partners involved to help establish the benefits of hospice in the community. So know your community well and others who can be of help in spreading the word. And make sure you also have staff willing to help promote and compassionately care for the patients who will come to your organization.



Hospice at Home:

Palliative Care and Transitions Programs

Hospice at Home, based in St. Joseph, Michigan, introduced a Palliative Care Service in 2006 and a pre-hospice Transitions program in 2009.

“Jointly, these programs provide our community with high-quality care, while also increasing referrals to our hospice program,” says Melinda Graham, MBA, CFRE, the director of development and strategic initiatives. “In general, our hospice admits an average of 10 people from these programs each month. The patients also tend to stay on hospice longer—the current average being 100 days.”

In the following interview, Graham talks about the agency’s experience since launching the services—both of which have also helped to increase donor engagement.

Tell us about your Palliative Care Service—how is it structured and staffed?

Hospice at Home offers a physician-led, home-based Palliative Care Service as part of its spectrum of care for seriously ill individuals. Our palliative care physician and an administrative scheduler are at the core of the service. Working in coordination with our Transitions Program and Referral Center, both symptom management and psychosocial support are offered through a variety of means. Our physician visits patients, families and caregivers in their homes, assisted living facilities, adult foster care homes and skilled nursing facilities.

Does it have a defined mission and focus?

In order to serve the growing number of patients with chronic illnesses, the physician visits focus on three things: relief from symptoms associated with the illness; assistance with understanding difficult treatment choices—from what to expect of the disease process to help with determining priorities and navigating the healthcare system; and collaboration with providers and physicians to provide consistent

health care and give patients a better understanding of their options.

How many patients are you serving?

In 2011, we served approximately 275 palliative care patients, and averaged eight new patients and 60 physician visits per month. This past October, our palliative care physician became full-time and our census almost immediately jumped to an average of 10 patients and 90 visits per month.

How do you get referrals?

Our palliative care referrals come from primary care physicians, oncologists, other specialty physicians, long term care facilities, and patients and families. We also receive referrals from our Transitions program and Hospice at Home's Referral Center when the patients are not medically eligible for hospice.

How much time is spent with patients?

After receiving a referral from a physician or a call to our Referral Center, our palliative care physician works closely with the patient's referring and/or primary care physician as well as the patient and family. The care begins with an initial 60 to 90-minute consultation, and follow-up visits of roughly 30 to 45 minutes. During a palliative care visit, our physician meets in the home with the patient and family to address symptoms, discuss goals, assist them with understanding the course of the disease, and help them establish realistic expectations.

Quick Facts About Hospice at Home

- Founded in 1981.
- Based in St. Joseph, MI.
- Serves residents of southwest Michigan.
- Employs 102 FTEs and 300 volunteers.
- Average Daily Hospice Census: 155.
- Opened Lori's Place in 2004, a community bereavement center for children and their families.
- Introduced a Palliative Care Service in 2006.
- Introduced Pre-hospice Transitions Program in 2009.



There is also frequent contact with patients and families in between these visits, whether it's for scheduling visits, refilling scripts, or addressing the possible need for transition to hospice. It's the continuity of care that is emphasized throughout the relationship, with the primary care physician and/or referring physician kept in the loop through visit dictations or conversations with our palliative care physician.

How is the service funded?

We have a Medicare part B provider number that allows us to bill Medicare, Medicaid, and most major insurance providers for the palliative care physician visits. Co-pays are billed to a secondary insurance and/or to the patient. We use a sliding-fee scale, so that patients who cannot afford the co-pay will not feel financial hardship and can still be cared for by our physician.

Tell us about your Transitions program?

In 2009, Hospice at Home purchased the Transitions program of Transitions PreHospice, Inc. It is a family support program where non-clinical staff and volunteers serve people who are coping with an advanced progressive illness.

A full-time Transitions coordinator and a part-time Transitions spiritual care coordinator work with volunteers to support the Transitions clients. The staff identifies their needs and helps connect them with community resources. But the staff also discusses such aspects of care as the emotional impact of living with an advanced progressive illness, and helps them set clear goals so care

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decisions reflect what is most important to them. The volunteers are also available to provide companionship and respite.

What works especially well are the Transitions/Palliative Care team meetings that are held weekly to discuss the individuals being served by both programs. It helps encourage valuable collaboration between the two programs.

Who are your referral sources for the Transitions program?

Some are hospice referrals who are not yet medically eligible for hospice, some are live hospice discharges, and others come to us from our Palliative Care Service when it is determined that they could benefit from Transitions. We also receive referrals from the medical community and from individuals who recognize a person may need Transitions support. In 2011, we served 375 people.

It sounds like there is real continuity of care between the services?

Yes, these programs have become our model for seamless care for seriously ill individuals. The beauty of these programs is that they are able to address patient needs from multiple directions, yet work in concert. With Palliative Care, patients receive a physician partner for the pain and symptom management that they need to live comfortably. With Transitions, people who need assistance planning and coordinating care and resources have the help that they need to connect with local agencies and programs.

What have been some of the quantitative benefits?

Jointly, these two programs provide the community with high-quality care while also increasing referrals to our hospice program. In general, our hospice admits an average of 10 people from these programs each month. The patients also tend to stay on hospice longer—the current average being 100 days. Both the

Palliative Care and Transitions programs also provide us with a formalized system to build a relationship with people who are not yet eligible for hospice care, yet could benefit from our expertise. It also allows us, as an organization, to continue our relationship with those patients who are discharged from hospice because they no longer meet the criteria of the Medicare Hospice Benefit.

What have been some of the qualitative benefits?

Our Palliative Care and Transitions programs have really helped us ‘widen our reach’ with many different constituencies—patients, physicians, volunteers and donors.

We have been able to have conversations with patients and their families earlier because they don’t have to give up treatment or other curative measures while receiving the services. It helps them to have someone come to their home to answer questions and discuss options. Whichever program they start with, they have people checking in on them frequently and making sure they have the appropriate level of care. It is especially helpful for those people who have several different doctors for various conditions to have someone looking at the big picture and helping to ensure their plan of care is in line with their priorities.

For our community physicians, it makes their work a little easier. They appreciate the extra time our Palliative Care physician can spend with the patient and family to discuss options and end-of-life care wishes. We have also found it helpful with volunteer recruitment, since some volunteers find it easier to work with Palliative Care or Transitions clients. It allows them to build longer-term relationships and to continue to volunteer for the patient if he or she transitions to hospice care.

And finally, the programs have given us reason to seek additional support from donors and grantors and, in so doing, has helped us cultivate more program ambassadors and a strong sense of ownership within the community.

What have been some of the challenges?

Our Palliative Care and Transitions programs have definitely evolved over time. We developed a palliative care business plan in 2004 and had a joint task force with our local hospital. The joint task force sent a team from both organizations to attend palliative care intensive training sponsored by the Center to Advance Palliative Care (CAPC). Unfortunately, the joint task force ceased meeting in 2006 without a joint Palliative Care program. So Hospice at Home began using a nurse practitioner to make palliative care patient visits and develop the program. We discovered that a physician-led program would be more effective and hired a palliative care physician in 2009. The challenge then became how to best utilize his time. We found that Palliative Care patients frequently needed assistance with connecting with community resources and finding ways to meet their daily living goals, and that led to our purchase of the Transitions program. This past year, we re-initiated working with the hospital to create a joint Palliative Care program—and we will formally begin a combined program this month.

What advice can you offer other hospice providers who want to expand into palliative care?

Evidence-based models now exist and more research is being published to help hospice providers establish and expand into palliative care. Our advice is to use this information and resources, such as those available through CAPC, to create a quality program that you can be proud of. We have learned that, in many cases, palliative care is the first contact that someone has with your organization. If that person is impressed with your care, he or she will trust you when it is time for

hospice care. If your palliative care service is not meeting his or her needs, that person will likely go elsewhere.

Do you have plans for future expansion?

Yes, we are one of three partners creating an independent PACE organization [Program of All-inclusive Care for the Elderly] since the integrated “PACE approach” to health and social services matches our strengths as a hospice and palliative provider. In partnership with our local Area Agency on Aging and our regional health system, the Area Agency on Aging building is being remodeled and increased in size to create a PACE day services center. This center will be the hub of PACE activities, including meal service and a health clinic to support the frail elderly and enable them to live at home for as long as possible. Our hope is to have the site open by July, 2012.

We are also affiliating with our local health system to create an advance healthcare planning program and expand our bereavement services throughout the continuum.



Hospice and Palliative Care of St. Lawrence Valley:

Palliative Care Partnership

In 2010, Hospice and Palliative Care of St. Lawrence Valley entered into a partnership with three area hospitals to help ensure that patients in need have access to palliative care. “While still a new venture, the results have been promising,” says Executive Director Brian Gardam. “It is helping to reduce hospital readmissions and, at the same time, helps demonstrate that palliative care should not be limited to only the last few months of life.”

In the following interview, Gardam discusses the new partnership—how it came about, the benefits and challenges of working with three hospitals, and its impact on hospice referrals.

How did this partnership come about?

The CEO of one of our local hospitals brought to my attention Medicare’s growing interest in reducing hospital readmissions. About 20 percent of people discharged are back in the hospital within 30 days, and studies were suggesting that up to 75 percent of these repeat admissions were avoidable. Research by Mary Naylor and Eric Coleman, as well as others, also found that it is effective to provide home follow-up after patients leave the hospital. So in 2005, we obtained a grant from the Alcoa Foundation and started a partnership with Claxton-Hepburn Medical Center in Ogdensburg. The project began with leadership from both our hospice and the hospital attending a palliative care leadership workshop at Hospice of the Bluegrass in Lexington, Kentucky. That was a really eye-opening experience about the possibilities of developing partnerships to provide palliative care.

We called this partnership the “Home Support Program,” since we wanted to differentiate it from hospice and no one in the community knew what



palliative care meant. By the time that grant ended in 2007, we had served a few dozen people. And while we didn't have enough data to prove it statistically, both our hospice and the hospital leadership were pleased with the results. We just needed to figure out how to create a sustainable program.

In 2010, I arranged a series of meetings with three of the four acute-care hospitals in St. Lawrence County. We brought our clinical and financial people together, including our medical director and each hospital's chief of staff, and talked about what we could do to provide a network to serve these high-risk patients after their hospital discharge. These are people who are not homebound and not on hospice and, thus, don't qualify for home care. They were falling through the cracks. I came up with a budget for a dedicated nurse-social work team to work with all three hospitals, and proposed that each entity contribute to fund the team. It made sense to the hospitals, so I had our organization's attorney draw up an agreement, and that's how we really got going.

How is the Home Support Program structured and staffed?

We have an experienced CHPN nurse, Sue Caldwell, and an MSW, Jill Deno, who are dedicated to the Home Support Program. They are talking every day with discharge planners and case managers at the hospitals. In the beginning, it took awhile for the hospital staff to understand the people we were trying to reach and serve. In fact, some of the patients initially referred to

Quick Facts About Hospice and Palliative Care of St. Lawrence Valley

- Founded in 1983.
- Based in Potsdam, NY.
- Serves residents of St. Lawrence County in Upstate New York.
- Employs 45 FTEs and 70 volunteers.
- Average Daily Hospice Census: 80.
- Introduced Palliative Care Services in 2002.



the Home Support Program really needed and wanted hospice, which was fine. For this palliative care program, however, we wanted people with a serious, chronic illness who had a prognosis longer than six months, who had difficulty understanding their disease and their treatment plan, and who had trouble managing their illness after they left the hospital. It has taken a few months, but our referrals have been increasing. We are now serving an average daily census of 13 patients, and our goal is 20.

Sue or Jill always try to see the patients before they are discharged from the hospital, so they can explain the program and get to know them. Then they arrange for a home visit within 24 hours of the patient's

return home. That's where the education really begins. While Sue and Jill are very skilled at explaining things clearly and making people feel they can take control of their health care, I also think it's easier for people to grasp such things when they are in the comfort of their own homes. For example, our patient satisfaction surveys often include comments like "No one ever explained this to me before."

Does the palliative care team face some of the same challenges as hospice staff?

Yes, I would say that's true. Most of the first home visit is devoted to reconciling medications—something that both hospice staff and palliative care staff are accustomed to. Another focus is getting these individuals to visit their attending physician. With patients being followed by

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hospitalists in the hospital, we often find that they are home before their doctor even knows they were in the hospital.

The social work issues that arise are also similar—empowering family members to provide support, linking up with resources available to patients, helping people cope psychologically with a life-limiting illness, and sometimes helping a patient find a safer place to live. We've learned that it is sometimes social isolation that sends someone back to the hospital.

How often does the palliative care team see home-care patients?

We visit patients weekly for 45 days, in addition to checking on them by phone. Forty-five days may seem like a short length of time, but one of the big reasons for the hospitals to invest in this partnership is to get patients past the 30-day timeframe without readmission since hospitals can't bill for readmissions within 30 days of discharge.

We are fitting in a lot of education within this short period of time—from helping patients develop coping skills to showing them how to navigate the healthcare system. On the other hand, our median length of stay on hospice is only 12 days, so accomplishing a lot in a short amount of time is nothing new for us.

What is your financial responsibility in the partnership? And how is that funded?

Each entity contributes an equal share which, this year, will be approximately \$35,000. Small grants and general donations, along with some philanthropy that is earmarked for palliative care, has helped us fund our portion.

Does your palliative care staff also work for your hospice?

The nurse and social worker have filled in for hospice staff who were on vacation,

especially when the Home Support Program was just getting started and the census was low. However, we have learned that it is very important to have dedicated staff for the palliative care patients. When we've done mixed caseloads, we have found that the pressing needs of the hospice patients take a lot of the staff's attention and short-change our palliative care patients. Our staff has also found it hard to switch gears between the two types of patients, with a different focus for their care.

Can you tell us about the palliative care patients you are serving?

Since last year, we've had 83 people in the Home Support Program. We are finding that about two-thirds of the people who are offered the services accept them. The people who decline are, on average, younger than the ones who accept. The most common diagnoses are heart disease, COPD and cancer, in that order.

While still a new venture, what have been some of the tangible benefits?

We have three-month follow-up data for 44 participants and 23 non-participants. We have had a 20 percent readmission rate at 30 days among the patients with heart disease—which is below the hospitals' average for this high-risk group. Fifty-two percent of the participants have had a readmission within 90 days, compared to 61 percent of the non-participants. We calculate that Medicare payments for the participants averaged \$1,650 less than would be expected—for a total Medicare savings of \$72,952. We think that's very promising. On the other hand, we have made no difference in the number of visits to emergency rooms. We have to work harder to encourage people to use our on-call system when symptoms flare up.

We believe that the program has also contributed to the growth in our hospice census. This year, our average daily hospice census increased from 70 to 80. While the Home Support Program can't get all the credit for this, we know of at least 10 patients who came to hospice through Home Support.

Is the partnership helping you develop more (or better) relationships with physicians in your community?

I think it has helped a great deal. We survey the physicians, and you know they can be tough critics. Sixty-eight percent have given us a "well done" and 24 percent have given us a "good" for "empowering the patient to avoid readmission to the extent possible for safety." It has opened up a lot of communication with them. We are often talking with them before they get the discharge report from the hospital. They can see we are a resource they can rely on to help their patients stay with their treatment plans.

Do you think this partnership is also helping to improve understanding and perceptions about "hospice"?

I think it has helped hospital staff understand that hospice isn't just for the last few days of life, and palliative care doesn't equal hospice. Working out care plans for patients is much more effective in giving hospital staff a clearer picture of what we do than any number of in-services we can provide. It also has given us a clearer understanding of what they are up against. Hospital case managers have huge challenges.

It makes a difference with the patients too. They seem to be okay with the idea that the Home Support Program's nurse and social worker also work for hospice, but that doesn't mean they're on hospice. And it has been very helpful to develop that relationship with patients who later come onto hospice.

What have been some of the challenges?

We ran into problems with New York State's Corporate Practice of Medicine Law. In 2007, we hired a nurse practitioner with a plan to provide palliative care consultation services, billing Medicare Part B and private insurance. Hospices in several states do this. However, in New York, it could be interpreted as setting up a medical practice that would violate corporate practice law. We had to drop our plans, but the Hospice and Palliative Care Association of New York State made this a priority advocacy issue. It took a few years, but finally, just this August, Governor Cuomo signed legislation making it legal for hospices to hire physicians and nurse practitioners to provide palliative services outside the hospice benefit.

A challenge for the Home Support Program has been educating the hospital staff on which patients will benefit from palliative care. As we go along, hospital staff are better able to identify appropriate patients to refer.

Poverty is also a big challenge. St. Lawrence County is a large, rural, low-income area. Many of the residents have to make tough choices and don't always put their resources into health care. For example, a lot of people haven't signed up for Medicare Part D and don't have money to buy their medications. That's a big education challenge. Sometimes the hospitals and physicians can get sample medications to help these patients until they can get something set up, and sometimes we can work something out with a pharmaceutical company. It is disappointing to have to discharge a heart disease patient who would benefit from further support, but can't be helped until he or she meets the criteria for hospice. There's always going to be gaps.

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What advice would you give fellow providers who may be contemplating a similar partnership?

First, remember that you are trying to get a hospital to invest in a program that, if successful, will reduce its number of acute-care admissions. That can be a hard sell. You have to help them think about the long-term benefits—how the Affordable Care Act is going to start penalizing hospitals for readmission rates next year, how CMS is going to keep raising the bar, and how Medicaid and the insurance companies are adopting similar policies. We all must learn how we can get those readmission rates down.

Secondly, remember that you bring a lot to the table. Hospice has lots of expertise providing holistic care for people with serious illness, in all kinds of environments. You can bring that expertise to people who are at an earlier stage in their illness, but are having a tough time coping. Some hospitals are developing programs to extend their reach to discharged patients, but hospices are already there. However, don't approach hospital leadership with a superior attitude. I've learned to really appreciate what the hospital staff and leadership do in their world too.

Do you have plans for future expansion or diversification?

We have just submitted a proposal to CMS to become a demonstration site under the [Community Care Transitions Program \(CCTP\)](#). This is a provision of the Affordable Care Act that is promoting partnerships between community-based organizations and hospitals to improve quality of care and reduce readmissions. This is exactly what we have been doing, so it seems tailor-made for us. The fourth acute-care hospital in St. Lawrence County has joined us in the proposal. It has been very exciting and stimulating to have representatives from all four hospitals meeting with us to develop the framework of a county-wide service. If our proposal is accepted, it will mean covering a larger geography with one or two more staff. We will really be an active partner in the acute-care side of health care, and that will support quality palliative and hospice services over the long term.



Carolina East Home Care & Hospice:

Case Management and Adult Day Services

Carolina East Home Care & Hospice began providing case management and adult day services for residents of eastern North Carolina over 10 years ago—more to fill an unmet need in a primarily rural community than for any other reason.

In the following interview, Executive Director Lynn Hardy discusses both services, including the benefits and challenges in today's fiscal climate.

When did you begin offering Case Management and Adult Day Services—and what prompted it?

In 1994, North Carolina mandated that each county have a “Lead Agency” to provide a Community Alternative Program for Disabled Adults (CAP/DA). These Lead Agencies are actually county departments such as health departments and departments of social services as well as hospitals. Our local hospital, Duplin General Hospital, agreed to serve as a Lead Agency, but asked our organization to assume the role and provide the services. A couple of years later, we added a Community Alternative Program for Children (CAP/C). Then in 1997, we introduced Adult Day Services, in partnership with the Duplin County Services of the Aged.

One of our organization's goals is to be the preferred home care provider within our community and, in order to help earn that distinction, we wanted to step up and fill the unmet home-care needs of underserved populations. The opportunity to provide the CAP and Adult Day Services were very much in line with that.

Can you tell us about the demographics of your service area?

We serve a seven-county area that includes Duplin County and the six contiguous counties of eastern

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North Carolina. It is a rural and relatively poor area. We have a high percentage of people over 65—higher than our state average. And the poverty level in six of the seven counties also exceeds the state average. There is also a significant military population in two of the counties we serve.

What do the CAP services provide?

Both CAP services—for disabled adults and children—provide assessments, care planning, and referral/linkage services, as well as monitoring and follow up. Both are also funded by Medicaid.

To qualify for the adult program, individuals must qualify for Medicaid and need nursing-home level care—but must also have family or friends who are willing to assist with their care.

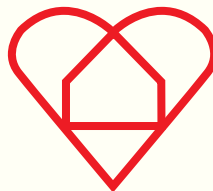
The program for children is for those under age 18 who qualify for Medicaid and require nursing home and/or hospital level care. Often, these children are vent-dependant, tube fed, non-ambulatory, and non-responsive, and are receiving private duty nursing from eight to 16 hours a day because their parents are employed outside the home.

How do you staff the services? Does your hospice staff serve dual roles?

Both the CAP and Adult Day Services are staffed separately from hospice, so no staff members

Quick Facts About Carolina East Home Care & Hospice

- Founded in 1984 as a home health agency, and introduced hospice care in 1986.
- Serves residents of eastern North Carolina—in the home or at its six-bed residential facility.
- Employs 76 FTEs and 54 volunteers.
- Average Daily Hospice Census: 54.
- In addition to hospice, provides Case Management Services for Disabled Adults and Children, and Adult Day Services.



serve dual roles. However, there are times when patients enrolled in hospice are also receiving CAP and Adult Day Services.

How many people do you serve a year? Who are your referral sources?

More than 150 adults and children receive CAP services each year. These individuals come to us from a variety of referral sources—physicians, other home health and home care agencies or hospices, nursing homes, pediatric clinics, hospitals, and sometimes from individuals caring for relatives at home.

In the current fiscal climate, has your Medicare reimbursement changed?

Due to state budget restraints, there is a limitation on the number of hours that can be billed for case management services. For adult services, for example, we can only bill

three hours per month, plus another three for the annual assessment. No additional hours can be billed for crisis management or a sudden decline in health status. The challenge is providing the quality care that's needed within this very limited timeframe.

Are you taking any proactive steps in anticipation of future cuts?

We have aligned our agency with other agencies in the state which are providing medical home care to Medicaid beneficiaries, such as Community Care of North Carolina, hoping

that, through collaboration, we can continue to provide the CAP services. While still early, the dialog has been both positive and promising.

Please tell us about your Adult Day Services?

The Adult Day Services provide a comfortable and safe haven for people with special needs whose family or caregivers work outside the home. The program provides for group and individual activities, lunch and snacks, and personal care services—all under the supervision of an LPN and CNA.

As I mentioned earlier, this program started out as a collaborative effort with the Duplin County Services for the Aged. In fact, it was really the brainchild of the Services for the Aged director who had wanted to fill this critical need for a very long time.

However, it was also part of our organization's vision when we opened our doors in 1984, though it was 13 years in coming to fruition. And it has most definitely been a struggle since the beginning, primarily due to the challenges of our service area—which spans more than 800 square miles. Without a large town that is centrally located within this service area, access has been a challenge. Our Adult Day Center, where all the services are provided, is located in the largest town in the southern end of Duplin County, making it difficult for people in other areas to attend. There is some public transportation through the county; however, it is often difficult to access at times that would best benefit the individuals in need of the services. Currently, we serve about 15 to 20 people a year, with no more than 10 in attendance on a daily basis.

What were the start-up costs?

We kept our costs to a minimum by renovating space in a building we already owned, which ran about \$50,000. For meal service, we utilize a nearby Senior Center while the County provides for transportation. Initially, staff salaries were paid for through a contract arrangement with the Duplin County Services for the Aged.

How are the Adult Day Services now funded?

Home and Community Block grants, allocated through the Duplin County Services for the Aged, fund the program. However, due to budget restrictions in the last few years, there has been a decrease in the grant funding which, in turn, limits our ability to serve as many people.

Do you utilize volunteers?

Volunteers do assist us at the Adult Day Center, mainly with the social activities. However, we also have one volunteer who assists with client care on a regular basis.

What are some of the benefits of providing Adult Day Services?

The benefits are in the individual stories. For example, the services enabled one couple caring for the wife's mother to go on vacation for the first time in many years. During their absence, the couple's daughter brought the mother to Day Care and, upon the couple's return, they continued to utilize the services, and went on to utilize the CAP services. Eventually, the mother required hospice and has since died. It also provided respite for man whose wife had dementia, enabling him to participate in church activities, run errands, and get needed rest so he could be there for her, fully, when she was home. There are countless examples like these. The benefits to the participants and the caregivers are immeasurable, but the benefits to the provider is another story. It is clearly not cost efficient.

Are there any benefits or cost-efficiencies in offering both the CAP and Adult Day Services?

Being able to serve community needs is the real benefit of offering both services. From an organizational standpoint, offering CAP services is more beneficial and more cost effective. We serve from 120 to 150 individuals a year and our reimbursement covers our direct costs. The individuals utilizing the CAP services are also more likely to remain at home, versus being

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institutionalized, and will probably eventually use home health and/or hospice services.

Were you to do it again, would you offer both services? And, if so, would you do anything differently?

Yes we would do it again. The CAP Services for Disabled Adults and Children continue to get support and recognition because they are non-institutional long-term care, and help reduce hospital admissions and visits to the Emergency Department. Our experience has also come in handy. We just participated in a pilot for CAP/Choice Services that enables the patient and/or caregiver to hire their own staff to provide the care. This program has now been introduced statewide in North Carolina. So, in having been a provider of the services, we have a good grasp of what's needed, and can empower the patient and caregiver to help themselves by providing practical guidance and direction.

In terms of Adult Day Services, had we been the only provider of the services, without funding restrictions early on, we probably would have opened more than one site, and that would have helped improve access and usage.

Do you have plans for further expansion or diversification?

We are looking at PACE, but are looking for partners in urban areas that would like to satellite a PACE site in a rural area. While future cuts to reimbursement are keeping us all up at night, we are facing the future with optimism—community-based care will continue.



Redmond-Sisters Hospice:

Transitions Program

Redmond-Sisters Hospice was founded as an all-volunteer program in 1981, serving just six patients per month. Today, it serves about 40 patients per day across the three counties that comprise Central Oregon. While it may be considered a small program by today's standards, with limited ability to diffuse the costs often associated with expansion, the organization had the foresight to introduce a Transitions program seven years ago that has resulted in some expected—and unexpected—benefits.

In the following interview, executive director, Rebecca Bryan, RN, MS, talks about the Transitions program and provides valuable perspective for many of NHPCO's smaller programs which want to expand, but may have reservations.

What prompted you to start the Transitions program?

Several years ago we determined that many of our patients and their families would have benefited from community-based services prior to needing hospice care. This was especially apparent for patients with chronic illnesses such as CHF, COPD and Alzheimer's as well as for cancer patients who were receiving treatment for their disease. Patients and their families were often not connected to many of the resources available to them; they also had no idea how to initiate those connections. Caregivers were often in such states of fatigue that they were becoming overwhelmed by issues that, with a little assistance, would otherwise be manageable. It was our goal to provide a service that could connect families to appropriate help and to provide volunteers who could offer respite, run errands and provide companionship to those who felt alone in their struggle to care for their loved ones.

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What services does it provide?

Our Transitions program offers non-medical assistance to members of our community who are dealing with the challenges that accompany a life-limiting illness. These community members are people who are either not yet eligible or not psychologically ready for hospice care. In fact, we refer to these individuals as “our clients” rather than patients because Transitions is a non-medical program.

Can you talk about the staff and their roles?

We employ a coordinator who meets with clients and their families to assess current living situations and to determine their needs. The coordinator then individualizes a plan specific to the household’s desired outcomes while taking into consideration the family dynamic and the needs of each member. That plan will usually include resource identification and, if needed, contact assistance and outcome follow up.

Our volunteers are one of our primary assistance resources. They are able to provide respite for the care giver and friendly visits to clients who may not have family as primary caregivers or who live alone. They may also run errands for clients; take them on outings if appropriate, given their physical abilities; and bring in Delta Dogs to provide pet

Quick Facts About Redmond-Sisters Hospice

- Founded in 1981.
- Serves the three counties of Central Oregon.
- Employs 30 FTEs and 80 volunteers.
- Average Daily Hospice Census: 40.
- Provides community bereavement services, including individual and group counseling for adults and children; Camp Sunrise for children, ages 7 to 14; and special programs such as Soup and Support.
- Introduced the Transitions Program in 2004.



companionship. They may also accompany the client to physician appointments where they can help a client with the questions he or she needs to ask as well as help with recall about the physician’s suggestions. Volunteers are vital to keeping the coordinator attuned to changes in a client’s status and needs so that other resources may be utilized.

The ongoing role of the coordinator is to maintain a high level of awareness regarding services that each client and his or her family may need. Examples of these services are home health services; Meals on Wheels; handy man or low-cost professional services in areas such as legal, financial, or Veterans benefit issues; and any other services that might ease the daily burden for the family.

We have also been blessed to have some very generous donations that help pay for services like massage therapy and acupuncture. These services are offered on an individual basis by way of assessment of the client’s physical needs. An example of this is a client with ALS who might benefit from massage therapy and acupuncture to help reduce muscle spasms. These services are often covered through the Transitions program depending on the client and family’s ability to pay.

A somewhat new component of our Transitions program is the offering of a palliative care consultation. Our hospice medical director, Dr. David Tretheway, is board certified in palliative care and has been a welcome addition to this effort. He has been instrumental in helping us to expand our service offerings in that he provides palliative consultations to Transitions clients as well as to the general public—but only on request. He also makes himself available to any local physician to discuss difficult cases. The goal of our palliative care consultations is to provide a course of action that addresses discomfort and pain regardless of the client’s choice of care.

Have you found that certain patient populations benefit most from Transitions?

We have found that individuals and families in our service area benefit most from Transitions when their disease poses daily life challenges sufficient to create hardship, but not sufficient enough to bring them onto hospice.

Two primary examples come to mind—clients with terminal cancer who want to continue on a curative course of action, and Alzheimer’s clients who do not fit the hospice admission criteria. In both of these cases, there is often caregiver fatigue which triggers the need to incorporate substantial community resources to stabilize the family. This stabilization also gives the family an opportunity to better understand the difference between palliative care and curative treatment.

Oftentimes, we receive referral paperwork from a physician’s office that says “Transitions/Hospice.” This might occur because the physician is unsure if his or her patient fits hospice criteria, but also recognizes that the patient and family need help. From that referral we can assess information that we’ve received, discuss the program options with the patient and their family, and help them to understand that as their disease progresses, we will be there to help them find the services they

feel they need to improve quality of life for the entire family unit.

How is the program funded? Do you charge patients for Transitions services?

Our primary expense is the salary of our coordinator. Redmond-Sisters Hospice absorbs this expense which is subsidized through fundraising events. The other expenses for massage and acupuncture have been funded through donations and grants to the program. Since our volunteers provide most of the “labor,” the program expense is minimal.

Does Transitions operate as a stand-alone program?

The Transitions program is a stand-alone program, which means that our coordinator does not do hospice work. The coordinator does, however, explain to potential clients the relationship between the Transitions program and our hospice as well as the Transitions relationship with other community hospice groups. If our coordinator believes, either in the initial stages of assistance or at a later time, that a client may be hospice appropriate, she will offer to contact the client’s physician to authorize a hospice evaluation. Any client wishing to receive hospice care is offered information about our hospice as well as other hospice groups, as requested, and the option to select their program of choice.

Have your hospice referrals increased as a result of Transitions?

It is difficult to assess whether the patient numbers have actually increased due to the Transitions program. Subjectively, however, we feel that we are getting patients from the Transitions program who are better prepared for the Medicare Hospice Benefit and have a good range of resources for help in the home. Access to those resources can only help a client and family be better prepared for end-of-life issues, more so than those who come onto hospice “cold turkey,” with a lot of unmet needs.

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Have there been any unexpected benefits?

We live in a rural area that has had a wonderful acceptance of hospice. Several years ago TIME Magazine noted that Central Oregon was “the place to go to die,” in part because of the abundance of hospices in the area and the number of patients here who take advantage of the Hospice Benefit.

What our Transitions program does is to take end-of-life care one step further by helping those who are dealing with chronic, life-threatening illnesses to better understand and accept assistance in the home. It also helps them to utilize appropriate resources in ‘their life transition.’ Moreover, it has helped people realize that they can seek help earlier in their disease process rather than waiting until just before they die.

The Transitions program has also been a benefit in helping us to recruit volunteers. Often volunteers want to help at hospice, but recognize that they want longer-term relationships and do not feel equipped (for one reason or another) to commit to those who may be on service only a short while or who are bedbound and restricted in some manner. These volunteers have an opportunity to work with Transitions clients and their families. It has increased our volunteer base and allowed volunteers to have a choice, based on their individual capabilities and preferences. Volunteers who want to work with hospice patients, but need time to adapt to a more intense end-of-life experience, find Transitions to be a helpful segue.

Has the Transition program impacted your work with community physicians?

Our physicians have been very accepting and, in fact, utilize Transitions to help the patient and family work through their assistance needs. Physician offices are often inundated with calls from caregivers who are struggling to work

through the myriad issues that come with a life-limiting illness. The Transitions coordinator can evaluate what is really going on in the home, give the family resource options that can help with day-to-day concerns, and can generally ease the path of change.

Physicians have also found that the coordinator and volunteers often recognize home situations that might adversely affect their patient’s (and our client’s) outcomes that other family members may not identify, such as confusion about medications, caregiver fatigue, and insufficient food. As families find satisfactory solutions to problems, caregiver confidence increases and calls to the physician’s office often decrease.

Physicians have also told us that they often find it easier to have the “tough” conversation with their patients and families when they can offer the option of Transitions or hospice, and that they will often start the conversation sooner. By bringing Transitions into the picture a bit earlier, the patient and family have time to adjust to the ‘cure to care transition.’

What have been some of the challenges?

With the local hospital system developing an inpatient palliative care program, we are finding it imperative to have the inpatient and outpatient programs find a system of communication that promotes continuity of care for patients/clients and their families. This is complicated by the fact that a patient may have a palliative care consultation in the hospital by the hospitalist and information is not passed on to the primary care physician in a timely manner. Providing a mechanism of communication between the three entities involved in the patient’s care can be complicated. Often the Transitions coordinator fills the role of information gatherer and coordinator at the time of a hospital discharge.

Any suggestions for fellow members who are contemplating similar expansion?

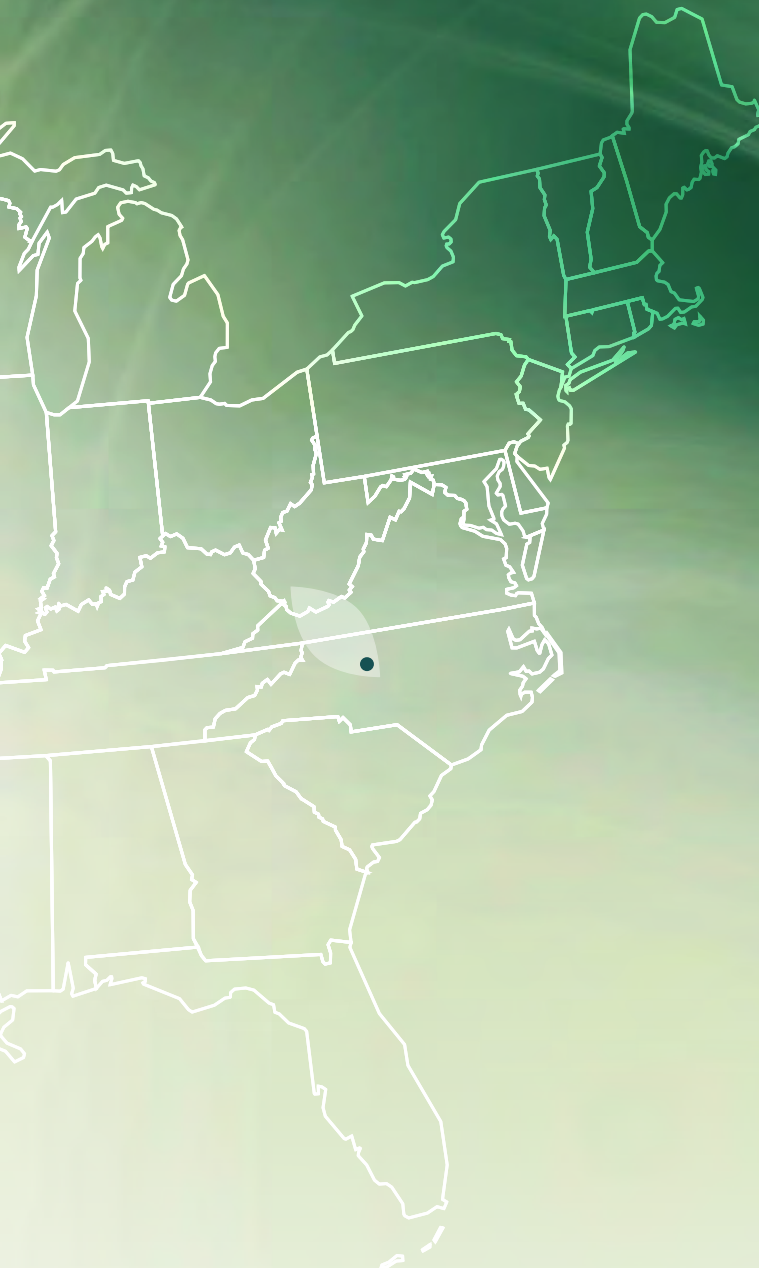
I would encourage anyone to consider the opportunity, not only for relationship-building with current referring physicians, but to also help educate those physicians who may not have an in-depth understanding of what hospice truly offers. By allowing physicians and others to become more comfortable with a less-intense help experience, we are able to build trusting relationships in a non-intrusive manner. That trust can only be beneficial to the client who may become a patient in the future.

Transitions offers so many opportunities to build community relationships on so many levels. While there may still be trepidation regarding end-of-life care, that concern doesn't exist for the non-medical assistance that the Transitions program offers. So my suggestion is this: If you are debating about a program, try it, if only in a very small way, and watch relationships grow and flourish.

Do you have other plans for expansion?

Yes, we are currently taking part in the NHPCO "We Honor Veterans [WHV] program. The program has allowed us to better serve our local Veterans by way of expanded resources for our staff and volunteers as well as through additional self-education about Veterans' needs. One of the goals of the [WHV] program is to encourage Veteran to Veteran volunteer options. What that means is that we are working to place local veterans with hospice patients as well as with Transitions clients. By incorporating this volunteer option into the Transitions program, we are encouraging longer and more fruitful relationships between Veteran volunteers and those Transitions clients who may eventually choose to make use of our hospice services. It goes along with the normal volunteer need to sometimes have longer-term relationships. [To learn more about WHV, and enroll as a participant, visit www.wehonorveterans.com.]

Hospice and Palliative Care of Greensboro:



PACE Partnership

“PACE of the Triad” is a new 18,000-square-foot health and human services facility in Greensboro, North Carolina that provides support to nursing home-eligible people so they can remain living in their own homes for as long as safely possible.

PACE is the acronym for “Program for All-Inclusive Care of the Elderly.” And, like other PACE sites, PACE of the Triad is a non-residential facility that includes an adult day health center; comprehensive, onsite medical services; and additional services such as transportation, home healthcare, and medications. PACE sites provide comprehensive care—and assume full responsibility for every aspect of each person’s healthcare once the person enrolls.

There are approximately 75 PACE sites in operation around the country, but what’s different about PACE of the Triad is its organizational structure.

Most PACE sites are managed by a single provider that will contract with other businesses for services they aren’t equipped to provide themselves. PACE of the Triad, on the other hand, is the only PACE organization formed through an innovative collaboration between a health system (Cone Health), a home-health agency (Advanced Home Care), a retirement community (Well•Spring), and a hospice—Hospice and Palliative Care of Greensboro.

The collaboration has been in the works since 2008 and, as of July 1 of this year, the facility has begun serving residents of Guilford and Rockingham Counties.

In the following interview, Patricia Soenksen, MBA, MA, the president/CEO of Hospice and Palliative Care of Greensboro (HPCG), talks about this innovative collaboration—and the planning and strategy that contributed to the site’s successful launch.

Had HPCG considered becoming a PACE provider before discussions about partnering started? And, if so, what prompted your specific interest in PACE?

In mid-2008, we first learned about PACE from HPCG Vice President Ursula Robinson, MHA, MSW, who presented the concept to our management group. We were intrigued by the fact that PACE and hospice share similarities. For example, both models support people being able to remain in their own homes as long as appropriate. Both models require an interdisciplinary group for the development of the plan of care, and both operate under a capitated reimbursement system for Medicare/Medicaid. [PACE is reimbursed on a monthly basis, per participant while hospice uses a per diem reimbursement model.] We also knew that a PACE program would eventually be developed in our service area by some organization and, therefore, we decided it would be better to be “at the table” instead of on the sidelines as the program was established.

How did the idea of a formal partnership come about? Who approached whom?

Shortly after we learned about PACE at our management meeting, we began to hear more about PACE at NHPKO conferences. But our first serious engagement occurred when we were contacted by Tim Clontz, one of the

Quick Facts About Hospice and Palliative Care of Greensboro

- Founded in 1980.
- Serves Greater Greensboro, North Carolina.
- Employs 183 FTEs and 267 volunteers.
- Average Daily Hospice Census in 2010: 327.
- Provides hospice care in the home, including assisted-living and skilled-nursing facilities, and at its 14-bed in-patient facility, Beacon Place.
- Other services include:
 - Palliative care in area hospitals (with full IDT support) and in assisted living and long term care facilities (physician and nurse practitioner support);
 - Supportive, home health and hospice care for children and teens; and
 - Community grief counseling.



HOSPICE and PALLIATIVE CARE
of GREENSBORO

executive vice presidents of the Cone Health System, a five-hospital system in our area. Tim assembled a group of local healthcare leaders to see if there was interest in studying the PACE model as a way to better serve the frail elderly in our community.

The initial steering committee included Tim Clontz; Steve Fleming, CEO of Well•Spring Retirement Community; Joel Mills, CEO of Advanced Home Care; Jan Capps, then-president of the Cone Health Foundation; and Ursula Robinson and myself. We were all passionate about elderly citizens in our community being able to remain in their own homes, maintain autonomy, and attain a maximum level of physical, social and cognitive function.

Ursula was a great addition to this initial steering committee because several years earlier she had investigated the development of PACE with a local aging agency but, at the time, there was inadequate funding to proceed. Ursula has since been named the new executive director of our PACE of the Triad, so we are especially pleased that a professional who worked in hospice care at HPCG for 18

years is now the leader of PACE of the Triad!

The Cone Health Foundation was also intrigued by the PACE concept because of its interest in

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local healthcare access. The Foundation encouraged our steering committee to apply for a planning grant. We submitted the grant to help pay for a PACE consultant to assist in the research and financial feasibility phases, and selected Palmetto Senior Care to provide the consultation services.

Had you already worked with any of your Triad partners—and had positive working relationships already established?

Yes, the partners were already well-known and respected by each other. Since 1984, HPCG has had a partnership relationship with Cone Health—half of HPCG’s board of directors have been appointed by the health system. And HPCG has also had long-standing contracts with Advanced Home Care and Well•Spring. Advanced Home Care operates 28 branch locations in North Carolina, South Carolina, Virginia and Tennessee, and Well•Spring, which was opened in 1993 by a coalition of nine local churches, is regarded as a very large and comprehensive provider of retirement community services.

Throughout the past three-year process of researching, developing and starting up PACE of the Triad, the partnership has been robust, collaborative, supportive and extremely positive among all parties. The Cone Health Foundation is not actively involved now beyond the generous grant funding they provided for the initial PACE consultant, but the Foundation remains very interested in the PACE model of care locally.

To learn more about this venture, visit the [PACE of the Triad website](#).



When Cone Health approached you about partnering, how did the process evolve?

All the partners informed their respective boards of directors at the time of initial inquiry and study of the PACE model, but at first no official board action was required—it was too early in the discovery process.

The study was a very careful, thorough research and analytical process that involved engaging Palmetto Senior Care, as I mentioned earlier. Palmetto was charged with completing a regional marketing assessment to determine if the local demographics of Guilford and Rockingham counties would be sufficient to support a PACE program and if so, then to help us develop a business plan and financial pro formas. We also did “due diligence” that included site visits to another nearby PACE program in Burlington, North Carolina, and one in South Carolina. We conducted conference calls with other PACE programs in the mid-Atlantic region, and our steering committee joined the National PACE Association to stay abreast of emerging trends and issues.

All partners then presented formal proposals to their respective boards for review and approval. The HPCG board reviewed all of the pros and cons of the proposal and after discussion, approved HPCG’s involvement with PACE because it was in keeping with our “innovative spirit over many years.”

What is the structure of the partnership?

The partnership became incorporated in 2009. Its structure has gone through several small changes over the past three years in terms of

membership interest percentage, but currently Well•Spring has 51 percent interest; Cone Health has 22 percent; Advanced Home Care has 22 percent; and HPCG has 5 percent.

PACE of the Triad, which serves Guilford and Rockingham counties, is designated by the IRS as a 501(c)3 tax-exempt organization and, this year, we were certified as an Adult Day Health provider and approved by CMS to operate as a PACE organization. To become operational, PACE organizations must enter into an agreement with CMS and the Division of Medical Assistance.

Does each of the four partners assume responsibility for a specific range of services?

Each partner, or member organization, has a contract with PACE for patient care services. Well•Spring provides a lunch meal and two snacks; Cone Health is one of the contracted hospitals for acute care, skilled nursing facility and medical specialist services; and Advanced Home Care will provide skilled nursing and personal care assistance. Our organization contracts with PACE for palliative care consultation and chaplaincy services.

Will some of your hospice staff wear dual hats, and serve PACE clients as well as hospice patients?

No, not at this time. A patient cannot be served under the Hospice Medicare Benefit and PACE at the same time.

One of the challenges in becoming a PACE provider is the start-up costs. Can you discuss HPCG's level of investment?

HPCG's initial investment was very modest—only 5 percent of the total estimated start-up—and we have not had any additional expenses beyond this initial investment. But as the program grows, all partners will assume risk at a level commensurate with their equity share. The bottom line is that HPCG's financial burden is very minimal compared

to the other partners. Our board weighed all the pros and cons and decided it was more advantageous to join the partnership. We will be closely monitoring to see if PACE negatively impacts referrals to hospice, although we believe there is documented unmet need for both programs—HPCG and PACE—in Guilford County, such that there shouldn't be much overlap.

What were the challenges that stand out most?

Overall, the partnership to date has been very positive. Because our PACE partnership just officially began accepting participants on July 1 of this year, it is too early to discuss specific challenges. However, we have all been surprised that the amount and degree of regulatory burden (approval process, oversight, etc.) are even greater than we had expected—and greater even than in hospice care. All of the partners are focused on insuring that the economics work for the program, long term. The financial viability of a PACE program is very volume-sensitive. Therefore, our feasibility projections and financial pro formas are critical factors to monitor. We feel good about the administrative and physician leadership and the staff that has been hired to date. The focus on quality has also been excellent from day one.

Looking back on the three years of planning involved, what makes you feel most proud?

I am most proud that four separate organizations could work together so harmoniously for a common good—to improve healthcare and quality of life for frail elderly in our community. We all worked very hard and enthusiastically to achieve this partnership. I think it helped that we all knew and respected each other before coming together—there was a strong bond of trust among us. And I am most proud that the partnership hired Ursula Robinson, a former hospice administrator and leader, to be the new “face” of PACE of the Triad—someone who is knowledgeable about and supportive of hospice care!

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Any final thoughts for providers interested in exploring a similar partnership?

We had four “like-minded” partners so the partnership has been very positive and collaborative, but I would not casually recommend this model. It requires partners who are all passionate about helping elderly citizens in a community remain in their own homes, maintain autonomy and attain a maximum level of physical, social and cognitive function.

All partners must also be strong financially, with access to capital and an ability to provide some in-kind expertise, support or resources in the start-up phase.



Learn More About PACE:

Websites:

National PACE Association

Past Conference Sessions:

Several sessions were presented at recent NHPCO conferences, and are now available on CD for just \$10 each (or as MP3 files).

To review or purchase the sessions, click on the hyperlink, enter the session number, and scroll to the session name:

Opportunities and Transitions within a Continuum

Karren Weichert and Candace Young

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PACE and Other Delivery Care Models

Karren Weichert

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PACE: An In-Depth Look at Market and Financial Feasibility

Thomas Stitt, Colin Higgins and Aimee Kindorf

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Samaritan Healthcare & Hospice:



Pre-hospice Services

This past May, Samaritan Hospice, based in Marlton, NJ, changed its name to Samaritan Healthcare & Hospice. “Our new name is a better reflection of who we are today,” says president/CEO, Mary Ann Boccolini. “It reflects our expanded mission to offer a range of care options for patients and families before they may need hospice.”

Samaritan has certainly taken that mission seriously. Over the past 15 years, the organization has introduced several care options to complement its traditional hospice services, including a Transitions program; grief counseling through a community-grief center; a geriatric care management program; and palliative care services for both children and adults.

In the following interview, Boccolini answers some key questions about Samaritan’s experience to help those programs considering similar expansion.

Your organization is clearly one of the frontrunners in thinking outside the ‘Medicare Hospice box.’ What was the first service you offered and what prompted the decision to take that step?

Our first non-hospice service was our Center for Grief and Loss which opened in 1999. We had already been offering the required 13 months of grief counseling and support to families of our hospice patients, but realized that people who had not used our hospice services could benefit from our staff’s expertise. So, we opened up our services to anyone in the community who was coping with a loss.

Now called The Center for Grief Support, it offers individual and family counseling on a sliding fee scale, a range of free grief support groups geared to different losses, what we believe is the area’s only therapeutic play/grief support group for three-to-five year olds,

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and even pet loss. We also do much work within our local school systems. This includes grief education, and onsite support groups and debriefings for traumatic losses such as teen suicides, prom-related car crashes, and the death of beloved teachers. We also provide PTSD counseling for active-duty military as well as veterans and their families.

After taking that initial step, what other ‘non-hospice’ services followed?

In 1999, we also introduced a Transitions program to provide options, resources and support for those patients in our community who have a progressive illness, but do not yet meet the criteria for hospice care. It’s a volunteer support system that is offered at no charge both during and after curative treatments, and helps patients connect with community resources and services. Each Transitions client is also offered the companionship and support of a trained volunteer.

Then, in 2004, we added a program with palliative and hospice services for those living with end-stage heart failure. Many people in the community still believe that hospice care is solely for cancer patients, so this program helps dispel that myth. It also takes into account, with specially trained staff and cardiac-specific protocols, that the

Quick Facts About Samaritan Healthcare & Hospice

- Founded in 1980.
- Serves five counties in southern New Jersey, covering more than 2,000 square miles.
- Employs 290 FTEs and 450 volunteers.
- Average Daily Hospice Census in 2010: 358.
- Opened Center for Grief and Loss and launched the Transitions Program in 1999.
- Opened the Institute for Education and Research in 2002.
- Introduced SeniorWise Care Management and Samaritan Palliative Partners in 2009.
- Expanded Palliative Partners into a physician practice in 2011 and renamed it Palliative Medical Partners.



trajectory of heart failure—with its ups and downs and frequent hospitalizations—is not necessarily the same as a cancer patient’s journey. That same year, working with the renowned Children’s Hospital of Philadelphia, we also introduced a pediatric palliative program, serving newborns and children through age 18.

In 2009, we expanded our services again with the introduction of SeniorWise Care Management, a non-hospice, fee-for-service geriatric care management program. Headed by a certified geriatric care manager, this program offers comprehensive in-home assessments and follow-up care coordination for frail elderly seeking to remain safely and independently in their homes for as long as possible.

That year, we also introduced the first model of our adult palliative care program, Samaritan Palliative Partners. While we’ve just made some significant enhancements, this early program was limited to home-based services.

Samaritan contracted with a company for nurse practitioner services to provide pain and symptom management for patients who were not eligible for hospice care. These patients also received the

benefits of our Transitions' volunteer support and referrals to community services.

What enhancements have been made to Samaritan Palliative Partners? And what prompted them?

This year we renamed the program "Samaritan Palliative Medical Partners," and made some significant changes. It is now a palliative physician practice which is staffed by our own dedicated team, comprised of a physician, nurse practitioner, social worker and program coordinator.

We believe that the physician-practice model engenders the highest level of respect from patients, families and other physicians, which provides the greatest opportunity to support each patient's personal treatment goals. As a patient with heart disease would be referred to a cardiologist, a patient with pain and other distressing symptoms would benefit from referral to a palliative medical specialist. Consultations are now available in the hospital and long-term care facility as well as at home.

The decision to make these changes was really prompted by several factors—the growing need we are seeing for non-hospice, hospital-based palliative medicine as well as healthcare reform's focus on coordinated community efforts to reduce unnecessary hospitalizations and improve the quality of care.

What level of investment was required to transition to the fully staffed Palliative Medical Partners? And how is the program funded?

The development of these programs was an outcome of Samaritan's extensive strategic planning process. Once the many expansion opportunities were evaluated, Samaritan's investment began with a thorough analysis of the external and internal factors required for success. Samaritan realigned its physician team and dedicated the services of Chief Medical Officer Stephen Goldfine to the Palliative Medical Partners service. We added nurse practitioner and social worker positions.

Administrative, financial and marketing systems were developed to support the program through existing departmental staff and resources. Program expenses are covered by budget allocations and public support; physician and nurse practitioner consultations are reimbursed by Medicare and many commercial insurers.

Would you recommend that providers today take a similar first step before taking on this greater investment?

I recommend strategic evaluation and analysis of any expansion investment to determine what is the best path for each organization. Feasibility studies are required to confirm the need for new or expanded services, and the organization must develop strong operational and growth plans to support and sustain the expansion efforts.

Can you also share the level of investment required in offering the SeniorWise geriatric program? For example, is it a stand-alone program? Do you reap cost savings by utilizing your hospice staff?

After confirming the need and analyzing growth potential, Samaritan was prepared to invest in the SeniorWise program by recruiting a certified geriatric care manager and aligning existing resources to support program development, administration, and financial and marketing investments. As per the program model, expansion efforts at significant milestones have been carefully planned to support continuous growth and eventual self-sustainability.

What are some of the primary funding sources for these initiatives?

Much support comes from memorial and tribute gifts from grateful families and friends, the creation of Loving Tribute Funds, and bequests. In addition, we receive grants from United Way, the Department of Military and Veterans Affairs, and various foundations. We also run three major fundraisers each year: a Celebration of Life gala in late February, a golf tournament in late June, and five Tree of Life celebrations during the first week of December.

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These fundraisers attract widespread corporate sponsorship. Over the last few years, we have also seen the growth of what we call “community fundraisers”—events run totally by community members or groups with the proceeds going to Samaritan. For example, this summer Samaritan will receive funds from a car show to benefit our outreach and service to veterans.

You noted that last year you received \$1.25 million of community support to help fund essential services not covered by Medicare, Medicaid and private insurance. Do you think your expansion into non-hospice services has helped you gain financial support from the community?

As a locally based hospice, Samaritan works hard to build and maintain strong community roots. Over the last 31 years, we estimate that our programs have embraced more than 50,000 families coping with illness and grief. So, first and foremost, we believe that the quality of our programs and the compassion of our care contributes to grateful families and friends wanting to give back to help others who will need the same services they just received. For example, this has resulted in specific support for our Center for Grief and our Transitions program. And, while the full scope of our broadened continuum has only been in place since January 2011, early indicators are that it is being well received by our community, which we feel will help continue and extend this support. With increased access to more services by more people, we definitely feel that Samaritan has broadened its base of support.

You also opened an Education Institute in 2002 to “advance understanding and practice.” Has the Institute had a positive ripple effect on improving the community’s perceptions about your services?

We believe it has. The impact of our educational outreach is evident in Samaritan’s growth, both in the number of people served and the services we offer. We’re proud to be in the top five percent of

hospices nationwide which admit more than 1,500 patients per year. The Institute offers evidence-based training for our own staff to keep their skills cutting edge, but we also offer a full array of continuing education programs, internships and field placements for our community’s healthcare professionals. This helps to build awareness for palliative and hospice care among current practitioners as well as the next generation of clinicians and therapists, including physicians. We also provide presentations for churches and community groups, veterans groups, and student groups to help create awareness, dispel myths and build timely access to services for all who can benefit from our care.

In general, have your expansion efforts improved access and lengths of stay within your hospice? Has any one service had the greatest impact?

Our Transitions program has been a way to increase earlier access to services for those who needed help but were not yet ready for hospice. This program, however, does not include hands-on palliative care. Because our expanded Palliative Medical Partners program just began services in January, it is still too early to gauge its full impact. However, the early results from this physician practice show increased hospice admissions, length of stay and census—very promising trends toward a more comprehensive hospice experience for our patients and families. Similarly, we have seen some hospice admissions develop from services for some of our ongoing SeniorWise Care Management clients.

Can you share any quantitative benefits from your expansion efforts?

Samaritan has always been very proactive about quantifying quality. With our hospice program, for example, we voluntarily have been accredited by the Joint Commission since 1998 and were among the early participants in NHPCO’s Quality Partners. We use NHPCO’s FEHC and FEBS surveys and also submit our data to

NHPCO's [National Data Set](#) so we can benchmark our programs, services and outcomes against state and national data. We constantly measure data from all our efforts to assess the impact of individual programs, but also how they mesh together as a whole. With our expanded programs, we have internally established quality protocols and routinely reassess their cost versus their impact on meeting our community's needs. So far, the strategic plan we have adopted appears to be on the right track.

What have been some of the qualitative benefits?

Our mission is always to increase access to care and our expanded services are providing more entry doors, so to speak. The early feedback from physicians, case managers and other referral sources has been positive. They tell us they find it easier to recommend palliative medicine as compared to hospice care because it is less stressful for patients and families to hear a recommendation for palliative medicine which can begin much earlier. With some cardiac patients, for example, the referral to Palliative Medical Partners can begin at time of diagnosis, when there is less stress and anxiety than at end stages of care. Also, the referral to our SeniorWise Care Management program provides physicians, case managers, elder law attorneys and financial planners with another community resource to assist families who may have specific caregiving concerns that are not appropriate for palliative or hospice care.

While the challenges of expansion differ depending on the service, were there any that stand out?

Since 1999, as we added each additional service, the challenges were just to develop a program structure that met a need and then monitor that program for ongoing relevance and quality. With each new addition, we weighed service expansion opportunities, balancing available resources with potential benefits, mission, operational and cultural fit, community needs, and so on. We tested each new program for its fit within our core values as an organization. Over the last two years, however, as the depth and breadth of those programs grew, the challenge became whether or not to actually change our identity to reflect the whole continuum.

There is always a risk in changing a name, logo, and corporate color that is well known and respected in a community. There are also costs involved in creating new materials, signs, etc. So there was much thought, research and soul-searching in evaluating this milestone move. But in the end, the need to let our community know that we are more than hospice, that we have more ways to serve them, made the risks and challenges worthwhile.

Any final thoughts or tips for providers who are now beginning to think outside the Medicare Hospice box?

Let your community's needs dictate your path and then focus on extending the same commitment to quality into those non-hospice services as Medicare demands for our hospice care.

Expanding Hospice Services Too

In addition to expanding into non-hospice services, Samaritan Healthcare and Hospice has also engaged in some creative partnerships to improve access.

In collaboration with the Jewish Family and Children's Service of Southern New Jersey, the organization introduced the Jewish Hospice Program, Sukkat Shalom (Shelter of Peace), in 2002. "Though Samaritan is non-sectarian, our name sometimes connotes a Christian focus," says Boccolini, "so, through this partnership, we're able to honor the richness of Jewish traditions and rituals." In addition to required hospice services, a Rabbi on staff provides spiritual support.

In 2006, Samaritan also launched Via Lucis (Way of Light), a Hospice Ministry for Catholic patients and families. "Roman Catholics comprise from 38 to 41 percent of our hospice patients each year," says Boccolini. "This program helps to sensitively address the sacramental needs and moral teachings of our single largest demographic. It is supported by an advisory committee made up of staff, volunteers and representatives from local parishes and the two Dioceses serving Samaritan's five-county service area."

Pathways Hospice:

Pathways Counseling Center

“The decision to open a community grief center is, needless to say, a big decision,” says Nancy Jakobsson, MSW, LCSW, the director of bereavement services for Pathways Hospice and the Pathways Counseling Center. “But I can also say it was well worth our time and financial investment.”

The Pathways Counseling Center opened in 2005 and provides grief counseling services to more than 1,400 adults and children annually, while also helping to cast a positive light on hospice in general and Pathways Hospice specifically.

In the following interview, Jakobsson offers helpful information for those members who may be interested in offering a similar service in their community.

What prompted you to open the Center?

We had been offering grief counseling, support groups and education to our community for more than 15 years. However, by 2002, the demand for counseling and support was growing at the rate of 10 to 20 percent per year. I knew that the demand had grown to the point where we either had to expand to meet the community’s needs or reduce the services we offered. We were out of space and our current staff members were at the peak of their caseloads. There was no other “logical or natural” organization which could or would meet the demand. We saw this as an integral part of our mission.

How long did it take and what was the cost to complete?

It took three years to raise the \$3 million we needed, and 18 months to build the Center. When we opened our doors in 2005, we had raised all of the funds.

How did you raise the funds?

Our marketing director organized a capital campaign that included a quiet phase in which we approached major donors, followed by an active phase that reached all areas of the community. We had more than 300 donors, including in-kind support and a 100-percent commitment from our board of directors as well as a significant lead contribution. The fundraising committee was comprised of both staff and members of our board of directors.

Can you briefly explain some of the initial steps you took?

We began with a community needs assessment that we sent to our referrers, including school counselors, clergy, private therapists, physicians, and past clients. We asked them what grief support services were needed, what they thought clients would be willing to pay for the services, if they saw this as a duplication of services and, finally, would they refer people to the Center.

Responses were both favorable and encouraging. The next step was to develop focus groups from the same population—and, again, the results were positive and supportive of us moving forward.

We then went to our board of directors for their approval, armed with 10 years of data, results from our needs assessment, and an initial business plan. We received unanimous approval and \$80,000 worth of pledges to the capital campaign.

Who assisted with the project—staff or outside consultants?

The capital campaign committee was led by our marketing director and included both staff

Quick Facts About Pathways Counseling Center

- Opened in 2005.
- Operated by Pathways Hospice in Fort Collins, CO.
- Serves residents of Larimer, Loveland, Berthoud and western Weld Counties.
- Employs 4 FTEs and a part-time administrative assistant.
- Offers two ongoing programs: Forgotten Mourners and Grief in the Workplace.

and members of the board of directors. We used an outside design team to help develop our fundraising materials.

During the building’s planning stage, we also involved hospice staff members and asked them to help us “dream up” the space, creating a vision with the architect. When the Center was completed, it included all of those dreams—four counseling rooms, two group rooms, a children’s room, an art studio, a community library, a teaching kitchen, an auditorium, and offices for staff.

What services are provided and how are they funded?

We offer counseling and support groups for adults, teens and children who have experienced the death of a loved one and for

those who are living with a serious illness. For community members, we have a sliding fee scale, while the families of Pathways Hospice patients can receive up to six counseling sessions and attend our support groups at no charge.

We are also a provider for many of the Employee Assistance Programs for the major employers in our area. This is a perfect fit for EAP services which offer five to eight sessions of counseling. We also have a grief support program for the area schools called Forgotten Mourners, and a Grief in the Workplace program.

We designed the building to allow for a variety of offerings. For example, the teaching kitchen allows us to offer cooking classes for widowed persons, while the art studio provides space for art and play therapies. We can also host our community memorial services right on campus, integrating art therapy and writing groups into the services.

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When you first launched the Center, how did you get referrals?

Our grand opening included a special invitation to our referrers, followed by visits to referring agencies and routine mailings to introduce the expanded services. We continue to send routine mailings to private therapists and other referring agencies.

What have been some of the quantitative benefits?

There has been a 15-percent increase in the number of our counseling clients, and a 25-percent increase in group participation.

What have been some of the qualitative benefits?

We have been able to expand our services to include art and play therapies for both children and adults and, as I mentioned, we have dedicated rooms for these services. The group and education rooms are also used by other community support groups and other local organizations which need space for meetings and workshops. The Center is recognized as an important community resource which has brought Pathways Hospice increased awareness.



Do you recall some of the early challenges?

As a community grief center, we needed to refine our intake process, scheduling protocol, and documentation to become a provider for the EAP network. We refined our fee collection process and initiated a sliding scale, and also required that all of our counselors become licensed professionals.

Now, five years later, have the services changed or evolved?

I think we will always be evolving in some way as there are changes in healthcare and hospice. We need to pay close attention to what clients need, and be willing and expect to adapt. For example, it seems people are less willing to commit to long-term groups, so we are now offering more short-term groups. The question is, how to remain current with the trends and to continue to be sustainable over time. Finding new revenue sources is always a challenge, especially in these uncertain times.



Southern Tier Hospice and Palliative Care:



LifeBeat Program

LifeBeat is the first of several diagnostic-specific programs which Southern Tier Hospice and Palliative Care (STHPC) offers within its three-county service area in Upstate New York. Launched in 2009, it is a cardiac-specific hospice program that is meeting the specialized needs of patients who have suffered heart failure, but do not yet ‘believe’ that they are candidates for hospice.

“Cardiac patients usually fall through the cracks of home care services, leaving them with few options other than going to the ER or facing further hospitalizations,” says STHPC’s Provider Relations and Family Services Director Robin Stawasz, BS, LMSW. “And this is where LifeBeat is helping to fill an important gap. Our specially trained hospice team offers 24-hour coverage, self-care education, and day-to-day monitoring that enables these individuals to remain at home longer.”

Since its inception, LifeBeat has helped to reduce acute in-patient hospital days by 34 percent while increasing the program’s cardiac patient census by 284 percent. STHPC’s average daily census has also grown 34 percent. Here, Stawasz and STHPC’s Home Care Nurse Case Manager, Suzanne Scheib, RN, BSN, CHPN, answer some important questions for those members who may be interested in providing a similar service in their community.

What prompted STHPC to launch LifeBeat?

We realized that we—STHPC specifically and hospice generally—were underserving people with non-cancer diagnoses. Hospice has grown out of an oncology model and that does not meet the needs of all patients. It is not a “one size fits all” kind of business. We saw that people with cardiac heart failure (CHF) required a different approach to symptom management and care than our traditional

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population. In addition, these patients and their healthcare providers were not inclined to consider hospice as an option for care. Nonetheless, these people were clearly in need of exactly what hospice does best—palliative care and symptom management. We needed to find a way to bridge that gap.

Can you tell us more about it—what it provides and how it differs from “hospice”?

LifeBeat is hospice. While it’s specialized to meet the needs of cardiac patients, it is still hospice. All of our *LifeBeat* patients are expected to meet the Medicare guidelines for disease progression and prognosis, just like all hospice patients. Our goal, however, is to admit patients earlier on in the disease progression, when they can still receive considerable positive impact from quality symptom management. We therefore strongly stress the Medicare clinical guidelines for hospice admission with healthcare providers, moving as far away as possible from the “six months or less” that trips up so many, especially with a disease as hard to predict as CHF.

We also re-examined how we define palliative treatment. When deciding what is included in a care plan, we look less at “what are we doing” and more at “why are we doing it.” If the goal of a treatment is symptom control and the provision of the treatment is not causing undue burden for the patient and is being administered in the most efficient manner available, some treatments that are normally

Quick Facts About Southern Tier Hospice and Palliative Care

- Community-based program founded in 1981.
- Based in Corning, New York.
- Serves residents of Steuben, Schuyler and Chemung Counties.
- Average Daily Hospice Census: 100-110.
- Employs 70 FTEs and 110 volunteers.
- Launched *LifeBeat* in May 2009.

not considered part of “hospice” become appropriate. This includes things such as hospitalization for IV diuretics if a patient has lost their oral route, and low-impact cardiac rehabilitation.

Our *LifeBeat* patients get all the benefits of hospice care with an added, aggressive program to monitor and respond to changes in cardiac status. People on *LifeBeat* are expected to check and record daily weights and vital signs. They are encouraged to follow a sodium-restricted diet as prescribed by their doctor and are expected to be medication compliant. These are the tools that best keep their edema, dyspnea and pain under

control. We work closely with the patients and their families to educate, to support and to respond very quickly to any changes which may lead to decline. We call the doctor with any changes in weight that is greater than 2 pounds in 24 hours so that edema can be aggressively managed, leading to decreased dyspnea, increased comfort, and improved functioning. We try very hard to help the patient help themselves and have found that teaching cause and effect in the disease process leads to greater compliance and greater success on the part of the patient. When patients and families understand ‘why’ something is happening, they feel empowered to take the necessary actions to maximize and maintain their level of function. When patients begin a final decline, we are there to help support them, and transition them to end-of-life care.

Why do you use the name “LifeBeat”?

For so many cardiac providers and patients, “hospice” means dying and it means cancer. So, for those with heart disease, the word itself automatically shuts the door. For this reason, we elected to market the program under a separate name that captures exactly what is special and unique about our services to this group of people, while keeping the lines of communication open. It allows people to take another look at hospice and challenges some of their assumptions. We do not hide the fact that this is hospice, but we don’t have to hit them over the head with it either. We liked the idea of a positive, life-affirming name for the program as well!

Which hospice team members provide the care and what special training do they receive?

The whole team is part of *LifeBeat*. Our clinical staff receives training in cardiac disease process, progression, medications, diet, and symptom management. Through this process, we combine all that is best about hospice with an added layer of cardiac specialty. Our social workers and spiritual care counselors are trained in the unique needs of the CHF population, and our LPNs are taught to evaluate cardiac symptoms and management.

How is LifeBeat funded?

Since these are hospice patients, we work with the standard hospice benefit systems. While we thought that some of these patients might be somewhat expensive to carry due to expanded care plans, long medication lists and such, this turned out not to be the case. Due to our ability to act proactively, effective symptom management and long lengths of stay, serving these patients has turned out to be extremely cost effective.

When you first launched LifeBeat, how did you get referrals?

We are fortunate to work closely with the nurse practitioner who manages Heart Failure Disease Management at the local medical center. She was

an early champion of our program and helped us to connect with the cardiologists in our area. We provided direct education to the local cardiologists and primary care doctors as well. We went to these providers with the simple question, “how can we help you manage these patients?” By doing this, we included the providers as an integral part of the design of the program and it has proven mutually beneficial. We have also drastically improved our partnership with local hospitals as this is the only program they have seen so far that significantly reduces their readmission rate. Once we showed them what we could do for them, the hospitals themselves were looking for ways to promote the program.

What have been some of the quantitative benefits?

The benefits of *LifeBeat* far exceeded our expectations. The number of cardiac patients we were serving tripled and now they make up more than a quarter of our hospice census. Our average length of stay for all patients has almost doubled to just under 60 days. We were predicting that our acute inpatient days would increase, given the frequency that CHF patients seek hospitalization. However, due to effectiveness of proactive aggressive disease management, our days actually decreased by a third, even with our increase in census.

What have been some of the qualitative benefits?

We have seen a significant improvement in the quality of life of our patients with CHF. They are staying where they want to be and avoiding the hospital as much as possible. They feel increased confidence in their care plan and their ability to manage the disease. Their symptoms are under better control. Both the patients and the families are less stressed and better prepared. Isn’t this what hospice is all about? In addition, our relationships with healthcare providers in the area have strengthened and our public profile has expanded.

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Do you recall some of the early challenges?

It was difficult, initially, to help our staff look beyond their traditional view of hospice to a broader mindset, one that focused on symptom management to maximize quality of life regardless of disease process. We found that, with CHF patients, effective symptom management led to improved function, which left many of our staff feeling that the patients no longer needed us. It has taken some time for us as an agency to recognize that good symptom management *is good* hospice care and should not be taken to mean that the patient is no longer hospice appropriate. We also needed to educate our providers that hospice can do more than care for people at the very end of life. For the patients, they needed help coming to grips with the fact that their diseases are life-limiting and that hospice *is not* there to displace their current medical management.

What are your plans to serve other diagnoses?

Later in 2009, we launched Living with Dementia, a hospice program specialized to the needs of dementia patients. That has been very successful in growing our partnerships with skilled nursing facilities. Recently, we launched our Breath program to provide care to people with respiratory disease. This is modeled closely on *LifeBeat* and we hope it will help us meet the needs of an even more severely underserved population—COPD patients.

Any final thoughts or suggestions for fellow members?

Change is hard and many people need time to acclimate. Make sure you provide frequent opportunities for enhanced education for your staff, and monitor closely to ensure that the protocols for treatment are being followed consistently. Our healthcare environment is changing. If hospice does not adapt and find how we best fit, we will be at risk. Diagnostic-specific programming is a powerful tool to keep hospice relevant and growing, while serving those who need our expert services.



Delaware Hospice:

Transitions Program

“We introduced the Transitions Program in 2003 as a way to better serve the community,” said Susan Lloyd, MSN, RN, the president/CEO of Delaware Hospice.

“About nine years ago, we had conducted a statewide survey to assess community interest in a stand-alone hospice center and, along with positive feedback about the center, many respondents also said they knew of people who needed help, but not the kind provided by traditional hospice,” she explained. “That planted the seed for the Transitions Program.”

Delaware Hospice’s Transitions Program is a free service that connects seriously ill people with local resources and agencies that will provide the support they need to help manage their illnesses on their own, in their own home. One 57-year old woman needed support to manage stage 4 breast cancer while coping with the end of her 20-year marriage and the birth of her first grandchild. Another woman, just 25, needed support and guidance following the shocking news that she had Lupus, after having just moved to a new city and into a new job that same year.

Lloyd says that Transitions meets a unique need in the community. “It was established to support individuals who were falling between the cracks—not appropriate for hospice, yet desperately needing assistance.” Here, she answers some important questions for those members who may be interested in providing a similar service in their community.

How does the Transitions Program work?

The process begins with a call from the seriously-ill individual, a member of his or her family, or a physician or friend. This person has recognized that support is needed to help the individual or family cope with the changes in their lives due to the progression of the illness.

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A Delaware Hospice *Transitions* coordinator strives to be responsive to every call, following up with a personal visit to the home to assess the situation. After looking at that individual or family's specific needs, the coordinator suggests and facilitates the placement of appropriate community resources.

For example, if food shopping or cooking is a challenge, perhaps that client would benefit from "Meals on Wheels." If transportation is an issue, the coordinator might connect the client with a community transport organization.

When possible, *Transitions* volunteers support our program by making telephone calls, visits, or possibly running an errand. For example, during a "check-in call," the volunteer simply asks the client how he or she is doing and listens for any significant change in the situation. Quite often, *Transitions* clients live alone and a visit to the home by the *Transitions* coordinator or a volunteer also means a lot to them.

Through visits and phone calls, we have learned that the simple gift of lending a "listening ear" has made a difference by providing a trustworthy outsider for the client to talk to about his or her fears and anxieties, or for the caregiver to talk about his or her heavy burdens.

Quick Facts About Delaware Hospice:

- Founded in 1982.
- Average Daily Hospice Census: 700.
- Employs 350 FTEs and 815 volunteers.
- Three office locations serve Delaware's three counties.
- Services are provided in homes, nursing homes, hospitals, and the Delaware Hospice Center, which opened in 2008.
- Launched the *Transitions* Program in 2003.

How do you manage to provide the service at no cost?

Delaware Hospice's primary cost for *Transitions* is the salaries of its three coordinators. Presently, there is one full-time and two part-time staff who serve as coordinators. The community supports *Transitions* through contributions to fundraising events and by making donations. Volunteers are, again, a great source of support. They bring hope to the home-bound clients with their check-in calls or visits.

So, is *Transitions* then a stand-alone program?

Yes, it's a stand-alone, non-medical program, with its

own staff. The *Transitions* coordinators do not work with hospice patients.

When you first launched *Transitions*, how did you get referrals?

Delaware Hospice serves all three counties in the state of Delaware, and we started slowly, with one *Transitions* coordinator serving Sussex County. We initially visited a local cancer center and met with physicians and supporting nurses to explain the program. They embraced the concept and began to refer clients. At the same time, we educated our own staff and volunteers about the program, and word began to spread and referrals grew at a slow but steady pace. As the program took root, local media took interest and articles about what we were doing appeared in all local newspapers, as well as opportunities to speak on radio talk shows.

Six months after launching the program in Sussex County, we hired a coordinator for Kent County, and then six months later added another in New Castle County.

Were there any start-up costs?

As with any service, there were initial costs involved in launching this program, which were programmatic and salary-driven.

Now that the program is in its eighth year, how many people do you serve each year?

As public awareness of *Transitions* has grown, we've experienced an increasing number of requests for support. In fiscal year 2010, we served nearly 500 clients.

In addition, we have launched a new educational website for *Transitions*—www.seriousillness.org/Delaware. It offers free resources for someone living with or caring for a person with a serious illness. The website features *Transitions*, along with educational articles, caregiving tips, directories of community programs for each county, links to national resources, a family blog tool, "Ask the Expert," and a monthly e-newsletter. The e-newsletter, called "Make Every Day Count," shares helpful information for family caregivers.

Do you recall some of the early challenges?

The greatest early challenge was simply getting the word out, and letting people know there was help available. It was important to clarify the difference between hospice and *Transitions*—"life-limiting" versus "serious illness," and "medical" versus "non-medical." It was also important to clarify that *Transitions* is a stand-alone program.

What have been some of the tangible, or measurable, benefits?

The *Transitions* Program is a resource to help seriously ill individuals meet their own goals. Staying in their own homes and remaining independent are the most common objectives. The fact that the number of clients enrolled in *Transitions* has continued to grow indicates that *Transitions* is meeting this need in the community.

What have been some of the qualitative benefits?

Because *Transitions* is such a worthwhile program, staff and volunteers experience daily the motivating factor that they are truly making a difference in someone's life.

Community awareness of *Transitions*, as well as other Delaware Hospice outreach programs, has been significant in helping the organization recruit new volunteers as well as serving to motivate donors and participants in fundraising events.

Any suggestions for fellow members?

Any provider interested in establishing a similar program should consider several things. Hire a full-time coordinator. Know and understand your community—and understand its geography. And, understand what resources are available and make contacts with those resources to ensure they understand how *Transitions* works. The program works best as a volunteer-driven program, so a strong volunteer base is also highly recommended.

This is a program designed to meet a need similar to what we do every day, but much sooner. Just as hospice care provides comfort and a better quality of life, *Transitions* encourages and promotes independence and quality of life by helping to meet the challenges of coping with a serious illness.



Midland Care:

PACE

“PACE is like hospice on steroids,” says Karren Weichert, the president/CEO of Midland Care in Topeka, Kansas. It stands for ‘Program of All-Inclusive Care for the Elderly,’ and essentially is a community based long-term care alternative to nursing home placement. The program serves individuals who meet state functional assessment scoring for nursing home eligibility, but wraps services around them to care for and support them in the community.

While PACE is not a suitable option for all hospices, Midland Care decided to become a PACE site in 2002, and launched its program in February 2007. Here, Karren shares some of Midland’s experience for those members who may be contemplating PACE as a possible revenue stream.

Why did Midland decide to become a PACE site?

In addition to offering hospice care, Midland Care had been offering adult day care in the community since the early 90s. Originally, we served only hospice patients, but over time began to get more community requests for adult day care for frail elders unable to stay at home alone during the day. This led to the addition of a six-bed respite center (not for hospice but for the community at large) as we encountered exhausted caregivers needing temporary reprieve from caregiving responsibilities.

We were also seeing changes nationally, regionally and locally that we began to evaluate in our strategic planning process—hospice regulations and compliance were becoming more costly to manage; reimbursement was threatened and predicted to decrease; length of stays were declining; and the number of competitors for the same hospice market was increasing. We knew we needed to consider diversifying our services.

So becoming a PACE site had a lot of appeal. In addition to drawing on our core competencies, it helped us address a real need we'd been observing for some time: those persons in adult day care who were slipping through the cracks in terms of their healthcare needs, those hospice patients and families who said "we wish we had called hospice sooner," and those palliative care patients who think hospice means giving up hope and waiting to die no matter how many times we say it doesn't.

Can you tell us a little about PACE—who's eligible and what it provides?

The criteria to qualify is actually pretty simple. One must be 55 or older; eligible for nursing home care as defined by the state functional assessment tool; and able to live safely in the community at the time of enrollment. One must also live within the PACE site's geographic service area. Because this is a Medicare and Medicaid program, one must also be eligible for Medicare or Medicaid, or be financially able to pay what those payors would have paid for PACE services.

PACE must manage—and is financially responsible—for every aspect of a person's healthcare once he or she enrolls. It must provide all of the preventive, acute, and tertiary care needed, and that can be a very long list. It includes adult day care; home support/home health services; primary physician and medical specialty services; medications and medical equipment; physical, occupational and speech therapies; dental care; inpatient and outpatient services; transportation; nutrition counseling and end-of-life care when needed. Essentially everything that would be covered under Medicare and/or Medicaid must be covered by PACE, with

**Quick Facts About
Midland Care:**

- Average Daily Hospice Census: 140.
- Employs 137 FTEs and 180 volunteers.
- Three office locations serve 16 counties in eastern Kansas.
- In addition to home care and a 12-bed hospice inpatient unit, it operates a 12-bed residential unit for non-hospice patients.
- Launched PACE in February 2007.

the care being managed through an interdisciplinary team, case-management approach.

Who pays for the PACE services?

PACE is reimbursed on a per member, per-month basis, and is a blended payment stream from Medicare, Medicaid and Medicare Part D.

Medicare payment is based on the medical frailty of the individual served. Medicaid is a negotiated amount with each PACE provider and its state administering agency. Medicare D payments are based on an annual bidding process by the PACE site to CMS.

The services not provided directly by the PACE interdisciplinary

team, including all ancillary services and medical specialties, are made available through contractual agreements and are the financial obligation of the PACE provider which is at full risk for all medical services. In fact, some programs purchase a reinsurance product to cap risk at certain levels.

What is the typical length of stay?

Nationally, the average length of stay is about 28 months (from the time of enrollment to the time of discharge). Based on our experience so far, lengths of stay average 18 months from the time of enrollment to time of death. Most of our discharges have been due to death or because the individual could not manage the cost of the program, including their participant obligation under Medicaid. It continues to strike me as unethical that a program designed for the Medicaid population is not affordable for them. In the state of Kansas, the participant can only retain \$741 dollars of their monthly income if they enroll in this program. Participant obligations range anywhere from \$0 to \$1,500 per month (this is one

Continued on next page...

of the elements that potential providers should investigate because it can significantly impact the rate of enrollment in the program).

Was making the transition difficult?

There are clearly many similarities between hospice and PACE, so it's not a giant leap. Both are patient centered, managed care and holistic in nature; both encompass the family unit; both require multiple contractual arrangements; and both require out-of-the-box thinking to meet needs.

PACE is, for the most part, palliative care—but with a much longer care trajectory than we usually see in hospice. So, the difference in the length of stay for staff who are used to caring for patients for only a few months—and the requirement to fully care for all the chronic and disease elements of the person's health—does require a very different intellectual and emotional skill set. We have been able to adapt our EMR to serve both programs and that has made the transition for staff members easier as they have not had to learn a new or different system.

In terms of the paperwork, the application process is quite cumbersome. However, we found most of the required components were elements we already had in place, including most of the necessary infrastructure. Interestingly, CMS regulations require a Quality Assurance Performance Improvement Plan for PACE which is almost identical to the new hospice CoPs. There is more emphasis on the PACE side for taking QAPI deep into the organization and identifying and capturing improvement opportunities throughout the breadth of the program. We have been able to develop our annual QAPI plan utilizing quality indicators applicable across the continuum of our services.

What are the start-up costs?

Since the heart of a PACE program is an adult day center, there will most likely be some

capital costs for any hospice program moving to establish a PACE site. Midland already had a campus of buildings, including the one we had utilized for our adult day care services. However, we embarked on a renovation of that building for PACE in order to provide a clinic, therapy area, and more bathrooms to accommodate increased census and programming. The total cost of the renovation was \$1.2 million. There was also the investment for clinic medical equipment, rehabilitation equipment, and transportation vehicles for the program. Depending on the resources already available to an organization, initial capital investment in building and equipment could range from \$1 to \$3 million.

At initial start-up, most of our PACE staff came from our hospice ranks. The social workers, nurses and home health aides were all hospice staff with an interest in the new program. This resulted in significant cost savings at the beginning, but also as the program has grown. Currently, we employ 27 full and part-time staff for 96 PACE participants. Two positions, a physical therapist and a dietician, are employed by Midland Care and shared across programs. Some of the 14 staff in the adult day program serve both PACE and community clients, but the majority are PACE participants. These PACE participants reside in seven of the counties within our 16-county hospice service area.

What were some of the challenges?

One of the most difficult obstacles was working with our state legislature to approve the program. That process took four years. Our board had the foresight to include PACE as an initiative in all three years of our strategic plan. A less persistent organization might have given up, but we were determined to bring the PACE option to our community. While not all states may require that same level of perseverance, the process will most likely take a minimum of 18 months to two years.

What have been some of the benefits?

PACE has helped us provide care to a new constituency and diversify our funding streams. It also placed us ahead of the curve for health reform. PACE meets many of the elements of an accountable care organization, chronic care management, and medical home. Over the course of the past four years, we have seen our organizational revenue mix transition from 90 percent hospice to 58 percent hospice/38 percent PACE/4 percent other programming (as projected for 2011). That said, some of the funding for PACE comes from Medicare, so there is always the possibility that it too will experience reimbursement decreases.

Any final thoughts?

I would certainly *not* encourage every hospice to consider PACE as part of a diversification strategy. It is a risk, so you first must determine if your organization could fiscally manage this type of undertaking.

Programs should also examine their mission, vision and organizational culture. There is a tremendous amount of work to be done internally to determine if PACE will be a good fit. The longer your hospice has been in existence, the more difficult it may be to evolve into a new dimension of care.

There is also a great deal of research required on the external drivers of PACE. Does your state have PACE as a Medicaid state plan option? How supportive of PACE is the state legislature and state administering agency? What's the criteria for financial eligibility for Medicaid and would there be participant obligation? What is the size of the potential pool of participants in your service area who would meet the age and the functional and financial eligibility requirements? Is there a single point of entry for elder services in the community? Who would refer?

Even though our state included PACE as an option under the Medicaid state plan, there was a lack of knowledge and understanding about PACE among our legislative representatives and the state administering agency. As a result, we also put forth a dedicated effort to educate them on the basics of PACE and the benefits to participants, providers and payors. We also had to get legislative approval on the number of participants we would be permitted to enroll prior to submitting our final application to CMS—and that legislative approval took three years.

If you decide that PACE is not the right fit, I would encourage you to assess what's going on in your community and, where possible, find ways to collaborate with PACE and other new models of care.

To Learn More:

Several sessions about PACE were presented at NHPCO's August 2010 conference on "Developing the Care Continuum"—and are now available on CD for just \$10 each (or as MP3 files).

To review or purchase the sessions: (1) click on the hyperlink, (2) enter the session number shown in the Keyword Search, and (3) scroll to the session name.

Hospice Pioneers in PACE?

Karren Weichert, Samira Beckwith and Linda Todd

[Click here](#) and enter **9F** in the Keyword Search.

PACE and Other Delivery Care Models

Karren Weichert

[Click here](#) and enter **12E** in the Keyword Search.

PACE: An In-Depth Look at Market and Financial Feasibility

Thomas Stitt, Colin Higgins and Aimee Kindorf

[Click here](#) and enter **13E** in the Keyword Search.

PACE: Pathway to Operations

Linda Todd and Jade Gong

[Click here](#) and enter **10F** in the Keyword Search.

Opportunities and Transitions within a Continuum

Karren Weichert and Candace Young

[Click here](#) and enter **3E** in the Keyword Search.

Adult Day Care: Opportunity for Diversification and Collaboration

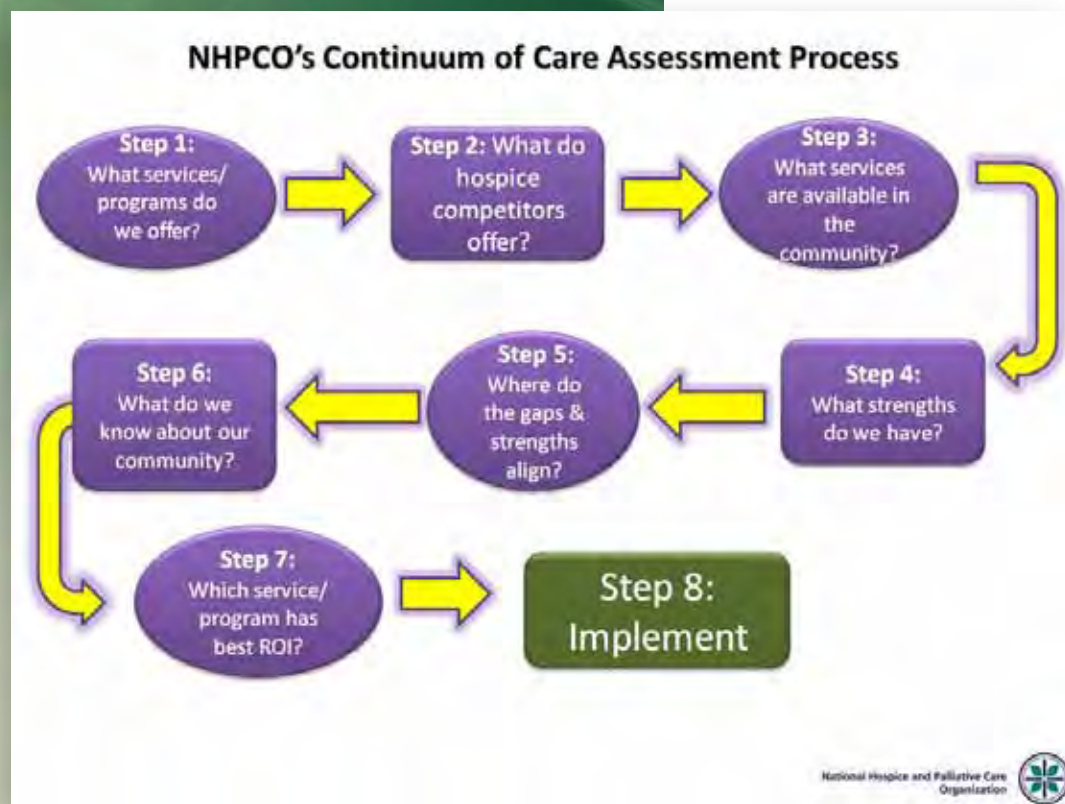
Karren Weichert

[Click here](#) and enter **4D** in the Keyword Search.

Free Community Assessment Tool From NHPCO

Those hospice providers which have the capacity and interest to expand services to meet unmet needs in their communities now have a new tool at their disposal—NHPCO’s [Continuum of Care Assessment](#).

Designed as an Excel Workbook, the Assessment guides you through an eight-step process to help you determine unmet needs and your ability to fill them, either alone or in collaboration with other providers. The eight steps, which are presented as separate tabs in the Excel Workbook, include:



1. Internal Hospice Assessment
2. Hospice Competitor Assessment
3. Community Services Assessment
4. Organizational Strength Assessment
5. Prioritizing and Mapping Gaps and Strengths
6. Community Data and Trends
7. Determining Return on Investment
8. Implementation

Keep in mind that the Assessment may take several weeks or

months to complete. To facilitate interdisciplinary perspectives and input, NHPCO recommends that you form a workgroup to complete the Assessment in collaboration with your organization’s leadership team and other stakeholders.

At the conclusion of the process, you will have detailed information about the types of services offered in your community, as well as the assets of your organization that can be leveraged to develop new services or enhance those you already have.

Additional Resources From NHPCO

- Palliative Care Consultant
- Clinical Practice Guidelines for Quality Palliative Care
- Providing Hospice and Palliative Care in Rural and Frontier Areas
- Operational Guidance: Hospice and Assisted Living
- Navigating Palliative Care, Manual and CD
- Enhancing Community-Based Options for End of Life Care: Adult Day Services
- Pediatric Care Resources (including information on pediatric hospice Medicaid services)

NHPCO believes that hospices are the experts in caring for people living with serious and life-limiting illnesses and encourages hospices that have the capacity to assess the need for new services in their community, with the goal of developing a seamless continuum of care.

A large, stylized leaf logo is positioned on the left side of the page. The leaf is light green and is set against a background of concentric, semi-transparent circles in shades of green. The overall design is clean and modern.

About NewsLine

NewsLine is a monthly digital publication for members of the National Hospice and Palliative Care Organization.

Each 40-page issue includes two key articles by leading experts and practitioners on various aspects of end-of-life care, as well as a “Voice of NCHPP” feature that provides interdisciplinary expertise and a “Hospice in the Continuum” feature that spotlights a hospice organization’s expansion or diversification efforts (from which the articles in this Compendium originally appeared).

NewsLine is one of the many benefits of membership. All past issues are available online at www.nhpco.org/newsline.

About NHPCO

The National Hospice and Palliative Care Organization (NHPCO) is the nation’s oldest and largest nonprofit membership organization representing hospice and palliative care programs and professionals.

NHPCO and its three affiliates — FHSSA, the Hospice Action Network, and the National Hospice Foundation — are committed to improving end-of-life care and expanding access to care through education and advocacy, with the goal of profoundly enhancing the quality of life for patients and their loved ones.

There are three primary categories of NHPCO membership:

Provider Members: Organizations which provide hospice and/or palliative care services.

Associate Members: Organizations that support and provide a service or product to hospice and palliative care providers and professionals.

State Hospice Organizations: State-based trade and advocacy organizations.

There is also a category for individual members. This category (NCHPP Membership) is for individuals working, studying or volunteering within the end-of-life care industry. The staff and volunteers of provider members are automatically enrolled as NHPCO-NCHPP members, free of charge, as an added benefit of provider membership.

For details about membership, visit the [NHPCO website](http://www.nhpco.org).

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