Increasing Your ‘Direct-from-Family’ Referrals

By Melinda Graham, MBA, and Tasha Beauchamp, MSc

In hospice circles, conventional wisdom dictates that you should get from 5 to 10 percent of your referrals directly from patients or their families. But what if you could get 20 or 30 percent—or even 35 percent—directly from them?

That’s what Hospice at Home in St. Joseph, Michigan was able to achieve after a concerted effort to raise its visibility and let prospective patients and families know that they can self-refer.

This article provides information and tips to help you work toward achieving similar results in your own community. (Yes, really—read on!)
Let’s Learn From Pharma’s Radical Shift

Since 90 to 95 percent of referrals come from the medical community (i.e., doctors, discharge planners and facility social workers), hospices quite logically concentrate their marketing dollars on these referrers. But introducing patients to hospice isn’t necessarily a job these medical professionals asked for. And it frequently is not a conversation they like to have. Physicians, understandably, do not like to tell a patient that there is no cure.

The result, however, is that hospices spend lots of money wooing reluctant gatekeepers. While 2011 data indicate a continuing increase in the number of deaths occurring under hospice care, the length of stay is decreasing. It’s not difficult to see how procrastination on the part of the doctor feeds the problem of late referrals, even though the research shows that longer lengths of service yield significantly better care.

Is it wise then to focus so much attention on medical referrers? As Albert Einstein once said, “Insanity is doing the same thing and expecting a different result.” Consider the pharmaceutical industry. In response to reduced face time with doctors, it began direct-to-consumer advertising. The result of this radical shift? Patients came into the office asking for “the little purple pill” and doctors prescribed it.

Hospice is unique among service providers in that the request can come from the patient or family, with doctor orders following. Physicians are generally quite open to fulfilling a patient- or family-initiated request for hospice. Not having to be the bearer of bad tidings helps the doctor move quickly past the potential morass of emotions and focus attention, instead, on the new goal of palliation.

Unfortunately, a 2012 national online study reveals that 55 percent of the community-at-large is not aware that a person can refer him- or herself to hospice. In response, more and more hospices around the country are taking a page from the pharma playbook and instituting a community-focused “Ask for us by name” campaign. This not only projects the idea that patients and families can choose hospice, but also addresses the misconception that there is only one hospice organization, much like United Way or Red Cross.

continued on page 4
As I write this message, NHPCO’s 28th Management and Leadership Conference is about to begin and I’m pleased to report it will be our highest attendance in five years.

Next month I’ll share feedback about the event for those of you who were unable to attend. The next Geographic Area Report, that will be emailed to primary contacts in late May, is another excellent source of information, especially on those issues discussed at the NHPCO board meeting which is held in conjunction with MLC.

While our national conferences—both MLC and the Clinical Team Conference each fall—provide an exceptional learning opportunity for leaders and staff, let me reinforce the priority that NHPCO places on education in general.

As we share in the NHPCO Annual Report, 59 percent of our expenses relate to work in the areas of education and engagement. In my view and that of the board’s, this is money well spent, and a reflection of the value we place on service and stewardship, two of the key values in our Strategic Plan.

So how is this money being spent? Let me highlight a few of the areas:

**Regulatory and Compliance Support:** In addition to tracks at our conferences, our Regulatory team keeps members up to date via weekly NewsBriefs, the Compliance Tip in every NewsLine, and through our Regulatory Alerts and bimonthly Roundups. “Regulatory Assistance” also responds to more than 4,000 individual inquiries each year, often on complex issues that require research and multiple contacts. The team also presents at state conferences and meetings around the country—to bring that support as close to your door as possible.

**Virtual Conferences:** Last year NHPCO hosted its first virtual conference on volunteer leadership. This provided a cost-effective opportunity for those who can’t afford to bring large numbers of staff to our national conferences. Feedback and attendance were tremendous, so we have planned our next virtual conference for this November on the important topic of bereavement services. Please stay tuned.

NHPCO also offers a Hospice Manager Development Program, as well as leadership and distance-learning opportunities. Please bookmark the Regulatory and Education sections of the NHPCO website to make sure you are fully utilizing all we offer. Educational programming is a benefit of membership, but also essential.

J. Donald Schumacher, PsyD
President/CEO
Plan and Act Strategically

The most successful hospices are those that are strategic in their promotion of timely, community referrals. They begin with a baseline and identify their target audience. They create a plan. And, optimally, they base their messaging on research specific to their service area.

1. Determine Where You Are and Where You Want to Go

You are probably already measuring where your referrals come from. However, you can also measure the percent of deaths you are serving in your community by determining the number of total deaths and dividing that number by the number of deaths you served. Through analyzing your donations and new volunteers, you can also calculate the percentage that came from families you served. All of these measures will probably lead to a hefty case for expanding your reach to more families.

2. Target Family Caregivers as Soon as Possible

Due to health challenges, people eligible to be patients in the near future are not likely to be engaging with media. It is their family members who are seeking health information. According to the National Alliance for Caregiving, the average family caregiver is a 50-year-old woman who works full time and provides assistance with instrumental activities of daily living (IADL) for her 77-year-old mother who lives 20 minutes away.

When you plan your campaign, look for media popular with this demographic. For instance, with purchased media (e.g., newspapers, radio, television), request company demographics and choose channels or times with high female, boomer-age engagement.

3. Make the Plan

Aim for an integrated campaign across several media. With all the competition for our attention, it takes multiple exposures to a message—think 20 to 50 times, not three or four—to actually make an impression in the human mind. Messages coming from several sources (e.g., radio, e-newsletter, direct mail, billboard, Internet) all during the same month or two are far more effective than picking just one medium, or spreading your message serially across the year, one medium at a time.

4. Draft Your Message Based on Research

Willamette Valley Hospice in Salem, Oregon hired a marketing firm well-versed in hospice care to learn more about the concerns and perceptions of family caregivers. “We thought we were doing a good job with marketing until Transcend Hospice Marketing conducted focus groups and telephone surveys for us,” said executive director, Pam Matthews. “Listening to these family caregivers really opened our eyes. We significantly changed our approach when we learned that key messages from past campaigns were inadvertently reinforcing misconceptions about hospice. Now we have messages that we know are on-target, as well as the baseline data to measure their effectiveness.”
5. **Language Matters**
Since earlier is better, it’s important to position your services within the appropriate time window. While accurate, “end-of-life care” is interpreted by the general public as being the last few days, or possibly weeks, of the patient’s life. The Center to Advance Palliative Care conducted a national opinion poll and found that “serious illness” was the most effective language for positioning services in the last months of an advanced illness.

6. **Use Your Stories**
In today’s world, people are bombarded with messages. Researchers estimate that an individual is exposed to as many as 30,000 marketing messages each day. Most of these we simply ignore. This is true of hospice care as well, especially in America’s death-denying society. So how do we break through the chaos and reach people that could benefit from our care? Sharing stories that create emotional connections with your target audience are one of the best ways to capture attention.

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Promote Your Message and Brand

Some of the traditional marketing methods that hospices use to reach their communities involve advertising on radio, television and print as well as via word of mouth. Let’s briefly review each.

Radio: This medium offers very affordable production costs because it utilizes the “theater of the mind.” Sounds and voice engage the imagination and allow listeners to fill in the blanks without the production expense of having to visually create the scene. Consider, for instance, radio spots with a worried adult daughter learning from a helpful hospice professional about services or situations that debunk common hospice myths. You may even be able to get some of the work done for free as part of the radio station’s quota for public service announcements.

Television: Although TV spots are expensive, there is no doubt that this medium reaches the largest segment of the population. It is uniquely suited to let the heart and soul of hospice shine through. “We were concerned that our board would balk at the cost,” Pam Matthews told us. “But they saw the benefits immediately. Our television spots have been very productive in raising our visibility.”

Print Advertising: People still read newspapers and magazines, especially those individuals in the older age groups, so print continues to be a strong way to share messages about hospice care.

For the best impact, just be sure to review the publication’s reader demographics and tailor your message accordingly. Consider implementing 90-day campaigns that reinforce one message at a time, using visuals that will resonate with the reader.

Word of Mouth: Your best advocates are frequently your employees, volunteers and donors. Encourage everyone to wear their nametag—and all their logo-wear—in public. Equip them with an elevator speech that ends with “just call us – we can help.” Provide print material that can be left behind. For example, Hospice at Home created wallet-size info cards that employees and volunteers can easily carry with them. As one employee noted, “Now I have something to give someone when I’m stopped at the grocery store and asked about hospice.”

Content Marketing

Content marketing has become an increasingly popular and effective means of reaching family caregivers earlier in the process. By providing families with branded educational information, you position yourself as the expert in family caregiving. With hospice inserting itself more prominently in the continuum of care, you might consider materials addressing generalized family caregiving issues as well as chronic conditions (not just the end-stage). This will allow you to engage with families upstream from the standard hospice window.

Below are examples of content marketing initiatives that are being used by various hospices throughout the country.

In Print: Touching Lives is a four-color magazine that provides educational and inspirational articles designed to reach family caregivers, so The Elizabeth Hospice has contracted with the publisher for exclusive rights to distribution within its San Diego service area.
The syndicated national content makes for a robust publication that’s a time-saver for the hospice. Christina Kalberg, the hospice’s business development manager, says the publisher handles the mechanics of production and gives them 12 pages of basic articles. They in turn focus their attention on fleshing out eight additional “local” pages to tell the hospice story and promote The Elizabeth Hospice brand.

On Radio: Dino Capestrani, director of marketing at Good Samaritan Hospice in Pittsburgh, has become a regular guest on the local radio show, “Health Talk,” which has a large older-adult audience. Dino comes prepared to speak about a specific topic in family caregiving, such as dealing with stress and getting help, but will also offer at-home tips for conditions such as CHF or COPD. However, the show can take on a life of its own when callers phone in to ask questions. Dino is able to answer their questions and frequently refers people to educational articles on the Good Samaritan website for more information.

Via “Caregiver College”: Through local research, Community Hospice in Modesto, CA, learned that people in their service area were simply not interested in talking about death and dying. In response, the organization decided to invest in a long-term brand-loyalty initiative that included monthly educational workshops about topics pertaining to family caregiving and chronic care (e.g., Heart Health, Family Communication, Medicare 101). The workshops, which are held during the day for seniors and in the evening for those still working full-time, are sponsored by local businesses which are also interested in building relationships with these niche markets. They have helped expand the perspective of attendees by encouraging them to begin talking about these topics.

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Branded Consumer Information from NHPCO’s Marketplace

NHPCO’s Caring Connections Program has developed an array of brochures and resources for consumers and caregivers—many of which can be purchased with your organization’s name and logo for branding purposes.

To learn more about NHPCO’s Custom-Print Marketplace, call us:
800-646-6460
(M–F, 8:30–5:30, ET)
earlier in the caregiver trajectory and, at the same time, have positioned the hospice as the caregiving expert in their service area. It’s a win-win for everyone involved.

**In Educational E-newsletters:** The educational e-newsletter helps you “touch” family caregivers each and every month while also being cost-effective and eco-friendly. That said, if you are thinking that the medium may not be appealing to prospective caregivers, who are presumably “older” Americans, consider data from Pew Internet and American Life: A little over 70 percent of all boomers (those adult daughters and sons) use email. Even their parent’s generation has embraced email, with 52 percent of people 65 and older reporting that they use this medium.8

Casa de La Luz Hospice in Arizona finds e-newsletters very worthwhile, so much so that it has licensed a monthly, syndicated e-newsletter that is focused on family caregivers. It has the ability to include local content, or not, as staff time allows.

In addition to the branding benefits, these types of newsletters also provide fresh patient education topics that community outreach staff can point out and discuss with physicians and discharge planners.

**Social Networking:** More and more hospices are taking advantage of the consumer engagement possibilities afforded by Facebook, blogging and other social media. While not yet as popular a medium as email, Pew data reveal that 33 percent of boomers now engage with social media.8

When it comes to blogging, Alive Hospice of Tennessee has been a pioneer. Over the past four years, the Alive Hospice Blog has featured a variety of staff-written posts which focus on various aspects of hospice care. Additionally, many posts have been written about volunteering, as well as special events and happenings. As with all social media, the public is encouraged to comment and dialogue on the issues too.

Similar to Alive’s blogging efforts, Hospice and Palliative Care Center in North Carolina uses its Facebook page to engage family caregivers. With close to 2,000 Likes, its Facebook page offers daily tips for family caregiving interspersed with posts about volunteer opportunities and fund-raising events.

**Other Possibilities**
- Willamette Valley Hospice in Oregon has an “elibrary” for family caregivers hosted at seriousillness.org/salem.
This syndicated content has 60 pages of information about medical concerns, emotional-spiritual issues, important decisions and local elder care services.

- Lower Cape Fear Hospice and LifeCareCenter in North Carolina have begun “Begintheconversation.org,” an Internet initiative with downloadable toolkits, resources and information about creative events supporting advance care planning.

Putting It All Together

Hospice at Home is one example of an organization that has yielded astounding results in direct-from-family referrals (35%) due, in large part, to thorough research and an integrated marketing campaign:

- Radio stories shared by patient and family members.
- Radio spots that emphasized “You have a choice in hospice. Choose Hospice at Home.” (The strategy very specifically emphasized that not all hospices are alike, ask for the program by name.)
- Weekly caregiver ads in area newspapers and caregiver-focused ads in the monthly health newspaper insert.
- Educational support groups à la Caregiver College. (In this instance, it was a syndicated program called “Powerful Tools for Caregivers.”)
- An e-newsletter for family caregivers.
- Educational posts on its Facebook page.
- An educational elibrary for family caregivers hosted at seriousillness.org/swmichigan.
- “Life Is Precious” stories—poignant exchanges which patients are willing to share through a weekly email to hospice staff, volunteers, donors, and community members who have registered for the communication. (The goal is to normalize the end of life and provide these individuals with word-of-mouth content that they can use to encourage community members to call the organization directly.)

But Marketing Isn’t the Whole Story

Hospice at Home’s direct-from-family referral success not only reflects fine planning and execution, but also a deep desire to change the culture. The organization’s vision is to have

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Americans view end-of-life care as a natural part of the circle of life, and hospice organizations as the experts in caregiving for seriously ill people so that, without hesitation, they seek our support.

As hospice providers, we need to think big. We need to challenge the old ways and reach out directly to our community. It is our responsibility to be the change we want to see in our world. That starts by expanding our own vision of end-of-life care and by empowering our community to call us directly.

Melinda Graham is the chief operating officer of Hospice at Home in St. Joseph, Michigan, and NCHPP’s Development/PR/Marketing Section leader. She is also working toward her PhD in leadership, with an emphasis on organizational analysis.

Tasha Beauchamp is the webmaster and research scientist for Elder Pages Online, LLC, a company dedicated to helping hospices make better use of the Internet. She is also a long-time member of NCHPP’s Development/PR/Marketing Section Steering Committee.

References:
4 Fox, S., & Brenner, J. (2012). Family Caregivers Online. Published by the Pew Internet and American Life Project and the California Health Foundation. Retrieved from the Internet 7/12/12.
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The Lighthouse of Hope Fund is available to hospice patients

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The use of mobile applications in the hospice setting are constantly evolving, almost as fast as the ubiquitous apps that are downloaded to iPads or iPhones every hour of every day. This rapid evolution is due, in large part, to the realization that mobile applications can help staff improve on the ways they deliver end-of-life care. Whether it’s a hospice aide performing the simplest of tasks or a nurse changing the care plan based on a patient’s latest vital signs, using mobile technology at the point of care allows staff to document and share information among the entire hospice team so everyone is up-to-date and onboard about the patient and family’s current status and needs. And this is in addition to the many operational efficiencies that can be realized, such as eliminating manual and paper-based processes and ultimately reducing errors and production time.

This article will discuss the benefits, particularly those you’ll find by using this technology in hospice home care.

The Digital Visit—Good for Everyone

When a hospice uses mobile technology, every patient visit is essentially transformed into a “digital visit.” By this we mean that the clinician can easily document information at the point of care, and can just as easily share it with the patient’s stakeholders, such as attending physicians, therapists, volunteers, aides and even family members. For example, the clinician can use the mobile device to collect vital signs or measure patient movements, and then use its built-in camera to share pictures or videos with fellow team members to obtain corroboration on the next best steps. Gone are the days when the hospice clinician has to rely only on phone calls and a single perspective on the patient’s condition. The clinician now has the ability to share patient data in real time to ultimately determine the best way to address the patient’s needs.
These benefits not only help the patient and the hospice, but also the patient’s loved ones. By providing them with such immediate information about the patient, each visit endears them to your program. They feel nurtured and loved, which increases the likelihood that your hospice will remain on the top of their minds. I can actually speak from my own experience concerning this point.

When my dad entered hospice care in 2005, I clearly remember each member of the hospice team doing their best for him. In my opinion, and in the opinion of my family, they were absolute angels. However, I can still picture the hospice nurse coming into our home with a two-wheeled hand truck in tow. She would use a fruit crate to hold her paperwork for the day’s visits which she transported from home to home on this hand truck. It seemed disorganized and disturbed me, so much so that I remember asking her about it.

Another memory that stands out was how my dad’s condition changed from day to day. The end of his life was an emotional rollercoaster for my entire family and, until we were able to make connections with the hospice staff, we were anxious and, understandably, afraid of what was happening and what lied ahead.

Of course, flash forward to today—with the benefits of mobile technology—and both the hand truck and telephone tag with hospice staff become non-issues. This new technology solves these issues as well as eliminates the risks involved with decision making at the highest and lowest levels of the organization.

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It Also Supports Compliance

Given the current environment, the days of monitoring your staff activity and patient visits via paper are simply ineffective, but that’s where mobile technology can help.

With today’s mobile applications, tasks can be accurately recorded and will never go incomplete. For example, a direct-entry model through a mobile device can increase the quality of patient care documentation since it helps eliminate the mental and physical errors associated with transitioning data from paper to an EHR system. Along those lines, this direct-entry model may be able to alert hospice staff if there are incorrect entries or forgotten visit tasks.

Care plans will also always match the visit notes—which is critical to compliance. And if an audit does occur, the mobile device makes it easier to share the records via the EHR system.

The Operational and Management Benefits

Using mobile point-of-care applications also enable more accurate tracking of travel expenses, better workforce management practices, fewer phone calls in and out of the office for schedule changes, and enhanced communications between team members. These and other benefits improve the hospice’s bottom line and support several key goals of today’s hospice leaders, namely to eliminate or reduce mistakes; accurately file claims; and improve audit procedures.

As a side note, I do recognize that when auditors arrive at your door, they still want paper documentation to do their due diligence, and this does undermine some of the paperless benefits of mobile technology. However, I also think that as our industry evolves, regulators will be forced to evolve as well and move away from paper-based audits.

Don’t Overlook the Human Factor

One of the key elements that gets overlooked with any technology solution is the human factor. Despite our desire to embrace technological advances, we are generally averse to changing the way we do things. I find this to be especially true among clinicians.
So the best way to bring everyone on board—and overcome their inherent fear—is to review the many reasons for implementation of mobile technology. And this must come from leadership.

Your leadership team needs to point out the benefits that will be gained by each person and department in your hospice. For example, staff will no longer waste time filling out paper forms that need to be manually entered into the back-office EHR system; schedules will always be up to date; office staff will no longer have to validate paper visit notes against the care plan or the schedule; and patient records will never be lost again. The benefits are many to staff at all levels—they just need to be articulated.

In fact, one the biggest surprises that a hospice typically realizes after implementing a mobile service is the improved quality of the data it receives from the field. Without mobile technology, a hospice must assume visit data is correct unless feedback from the patient or family suggests otherwise. A mobile service, on the other hand, allows your hospice to manage staff proactively, and even call ahead to the next patient if visits are running late.

Improved safety is also worth noting. The Global Positioning System (GPS) available with most mobile services can greatly enhance the safety of individuals working alone. Office staff can monitor mishaps on the road, from a traffic accident to a breakdown, and support the field staff appropriately while arranging for backup coverage at the patient’s home.

Lisa McCoy, director of clinical information systems at Tidewell Hospice in Sarasota, FL, is a strong proponent of using mobile technology in the home health setting, having seen excellent outcomes in documentation and productivity among its home health aides.

“We’re able to review the care plan prior to the patient visit and, because documentation occurs at the point of service, it’s more accurate” she says. “It also allows the aide to immediately contact the nurses with any changes, and also captures the exact length of each patient visit, mileage traveled from patient-to-patient, and the aide’s location throughout the day. In fact, it has increased the efficiency of our aides since it decreases the need to return to the office to enter documentation by an average of two hours per day. That time is now spent directly on patient care.”

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MDM for Secure Use

Of course, the importance of security cannot be overstated when it comes to implementing a mobile service, especially given that patient records are involved. However, those who claim that their paper-based processes are more secure than mobile applications are in for a shock.

Mobile devices used in hospices and in other healthcare settings should be equipped with Mobile Device Management (MDM) services that can control and even wipe clean all data if the device is lost or stolen. As an added precaution, many agencies have hired mobile strategists and mobile application champions to be the point people in the event these solutions fail, new employees require training, or the devices need to be reprogrammed or wiped.

Tips When Shopping for a Mobile Service

The applications you choose as part of your mobile service will provide different ways for you to share information across the hospice and to the patient’s family members.

For example, a hospice using Health Information Exchange (HIE) can securely share real-time visit information with family and friends who may be separated by hundreds or thousands of miles. By using a mobile application that sends information back to the office as well as to these portals, a family in Arizona can see what is happening to grandma in Florida—a view as to what kind of care that patient is receiving.

These types of services will provide a new level of visit intelligence to the patient, their families and hospice staff that would be impossible with paper and manual processes. They also differentiate the hospice from others, providing a competitive edge. It’s also invaluable intelligence to hospice staff since they can see what is happening to all of their patients by having secure access to the same family/patient portal.

So how do you go about selecting a mobile service—and the right applications? Here are a few tips to get you started.

1. Determine Your Goals and Priorities

Is it to improve customer satisfaction? Increase worker productivity? Better data collection and accuracy? Streamline workflow throughout the organization? Reduce operational costs and gain better accountability of staff? Any and all of these reasons may be your success criteria.

2. Select the Right Device for the Intended User

Make sure you select the right device for the intended staff. For example, a nurse may need a device with a larger screen size than a hospice aide.

3. Provide Adequate Training

The applications used by staff in various areas of your operation may be completely different. So recognize that you will need to train them on the applications as well as the device. Also, even though a device may be a pocket-sized unit, expect to train just as long and hard as you did when staff first learned how to use a PC.
4. **Make Sure the Device has Security Safeguards**

As I noted earlier, make sure the devices you select have the ability to lock down client data and stop the downloading of applications that you don't want your staff using. Again, this is done via Mobile Device Management (MDM) which basically allows “remote control” of the devices. With this safeguard in place, it also means that lost or stolen devices are no longer a concern.

5. **Decide if You Want Native or Cloud-based Applications**

Cloud-based apps may require connectivity to a network in order to function, while a native application can collect, store and forward information in and out of coverage areas. However, there are pros and cons associated with each—so research both options carefully.

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**Closing Thoughts**

In this decade of the Affordable Care Act, our collective goals will be to reduce the costs associated with each visit, maintain patient privacy, and yet still deliver high-quality care. Personally, I believe quality means knowing that the special and unique needs of each individual entrusted to your care are being attended to, and that the quality of care delivered is based upon the most up-to-date diagnosis and visit data. This makes the use of mobile technology not just an asset—but a necessity. Better knowledge and better communication will lead to better delivery of high-quality end-of-life care.

Scott Herrmann has more than 25 years of experience in application sales, marketing, and mobile technology. He currently serves as the director of mobile solutions for Procura, where he specializes in services for the home healthcare setting. You can reach Scott at sherrmann@goprocura.com.
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Health Planning & Development, LLC and Summit Business Group, LLC have created new Hospice State Profiles that include the 2011 Medicare data.

Each State Hospice Profile delivers critical information to any hospice executive interested in learning more about the competitive environment of their state. Developed exclusively for NHPCO Marketplace by companies with more than 50 years of combined hospice experience, each State Hospice Profile provides vital county-wide information for strategic planning, feasibility studies, or for anyone who wants to learn more about the development of hospice providers in each state.

Each profile includes:

- Comparative hospice penetration data
- Summary overviews of the major hospice provider in the county
- Analysis of location of hospice service
- Average length of stay for hospice patients in each county
- Analysis of Medicare enrollments, death rates and hospice patients
- Market share analysis by major providers in each county
- Trended penetration rates of hospice care in each county
- Influence of specific factors on hospice care growth
- Analysis of market share trends

As an added bonus, each State Hospice Profile also contains a National and Statewide Profile of hospice care based upon the last 11 years of Medicare claims data, including the most recently available 2011 data. The National and State Profiles include such information as penetration rates, estimated Medicare Cap usage, distribution of hospice census by location of service and other important data.

Order Your Copy Today!
According to NHPCO’s latest Facts and Figures, dementia is now the second most common non-cancer diagnosis served by hospice.

In this feature, two hospice clinicians provide valuable guidance to help your staff understand this complex and often-misunderstood disease.

In the first article, Dr. Lena Smith, the chief operating officer and clinical director for Retreat Healthcare in Albuquerque, provides a medically focused overview of the four most common forms of dementia.

In the second article, Reverend Carla Cheatham shares her own journey in learning about and caring for those with dementia. “It’s been both amazing and gratifying,” she says.
As the baby boomers age and enter the cohorts of senior Americans, we see the general media focusing more on elder health and other aging issues.

For the aging issue of dementia, it has helped tremendously in the last number of years that famous names and their families, such as Maria Shriver, Ronald and Nancy Reagan, and Glen Campbell, have told their stories of living and coping with this disease. Yet for the general public, the very notion of dementia—especially Alzheimer’s—creates understandable anxiety.

Overwhelmingly, people want to live a long life if there is quality in that longevity, but living with dementia can make this more difficult. The options for treatment are limited and the fuller explanation of why the incidence of dementia increases with age is still not fully understood.

So it’s helpful for families to learn more about the varying types of dementia as they seek support in strategies to cope.

As healthcare practitioners, we are learning new information every day and continue to hope for more options for the relief of pain and distress that this devastating disease often causes. In this article, I share some of the key information we now know. Because, as Hippocrates suggested, we can’t always cure, but we can comfort.

First, An Overview

Broadly defined, dementia is a syndrome of acquired intellectual impairment produced by brain dysfunction.¹ According to the 2012 World Alzheimer’s Report, there are over 36 million people living with a dementia worldwide—and the numbers are growing. Unless there is a cure or a treatment that delays the onset or progression, it is estimated that there will be 646 million new cases in the next 40 years.²

Dementia predominately affects older people, and the likelihood of developing dementia roughly doubles every five years after the age of 65. Consequently, persons over the age of 85 are considered to be at highest risk. The overall incidence and prevalence of all the possible causes of dementia are now being extensively studied.

The following two differentiating dementias stem from two of the most common identifiable causes of dementia: Alzheimer’s disease and vascular dementia. 

Difficulties arise in differentiating these two types of dementia because the onset is often gradual and overlapping and the symptoms may not be consistent. 

Dementia: A Closer Look

By Lena Smith, PhD

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dementias is not truly known since diagnosis is usually made after the mild levels of the disease have passed. Therefore, the numbers used for prevalence are most likely conservative and do not account for the full impact on the communities and families providing the care. Dementia has been identified as a health problem of “epidemic” proportions, with nearly half of those over 85 having some form of a dementing illness.

The diagnosis of dementia still depends on a good assessment and clinical judgment. There is no specific test, but rather an experienced practitioner takes a full history, assesses the clinical presentation, and completes the evaluation with mental-status testing, neurological examinations, and laboratory testing when indicated. There are situations where neuroimaging and neuropsych testing can add to the final assessment. The differential diagnosis between the dementias is largely related to common characteristics associated with Alzheimer’s disease, vascular dementias, Lewy body dementia, Frontotemporal dementia, Parkinson’s disease dementia, and Huntington’s disease or the other rarer forms. It is important to get an accurate diagnosis as soon as possible. Early diagnosis gives families an opportunity to plan for the future, evaluate environmental changes that may enhance safety, and experience benefits from the medications available.

**The Four Most Common Types**

**Alzheimer’s Disease**

In 2010, the Centers for Disease Control and Prevention ranked Alzheimer’s disease as the sixth leading cause of death. There are many forms of dementia, but Alzheimer’s disease is the most common type, accounting for approximately 50 to 60 percent of all cases.

The first case of the disease was identified in 1906 by Dr. Alois Alzheimer, when he presented to a group of German psychiatrists the case of Auguste D, a 51-year-old woman with a wide range of symptoms which included memory impairments, difficulties with language, disorientation to circumstance, hiding objects, and some paranoia.

Dr. Alzheimer maintained concise notes on Auguste’s deterioration and her final death. He also reported the histopathological findings of the cell abnormalities we know today as amyloid plaques and neurofibrillary tangles.

The DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition) provides clinical criteria for the diagnosis of dementia of the Alzheimer’s type. To meet these criteria for dementia, the symptoms must include decline in memory and the decline in at least one of the following cognitive areas:

- Ability to speak coherently (aphasia)
- Recognition or identification of objects (agnosia)
- Execution of motor activity (apraxia)
- Ability to think abstractly, make sound judgments, and plan tasks (executive function).

The loss is identified as gradual, yet continuing over time and not due to other conditions of the central nervous system, other systemic diseases, or substance-induced conditions.

Alzheimer’s often progresses through distinct stages
characterized by a prolonged trajectory of severe disability. By the final stage of Alzheimer’s, cell death is widespread and brain tissue has shrunk significantly.

Today, one in eight older Americans has Alzheimer’s and as the proportion of older Americans increases, so does the number of families that must assume the role of caregiver. [This past year, President Obama presented our first national plan to address Alzheimer’s disease. To learn more, visit www.alzheimers.gov.]

**Frontotemporal Dementia**

Frontotemporal dementia (FTD) is an umbrella term for a heterogeneous group of clinical disorders that follow a different clinical course from Alzheimer’s and have no distinguishing microscopic abnormality of cells that can be linked to all cases. It affects the frontal and temporal lobes of the brain and may account for up to 10 percent of all cases.

Generally, FTD is characterized by progressive behavior or personality decline, progressive language decline, and/or progressive motor decline. Some of the more common diagnostic terms include Picks disease; Behavioral variant FTD; Progressive nonfluent aphasia; Semantic dementia; Coricobasal syndrome; and Progressive supranuclear palsy. Patients with FTD often follow a pattern of gradual and progressive changes in behavior or gradual and progressive language dysfunction.

The most common behavioral characteristic of FTD is a lack of insight or difficulty in assessing social expectations. The lack of inhibition caused by damage in the front and side regions of the brain result in impulsive behaviors, such as swearing or yelling. The inability to transition may also result in compulsive or repetitive behaviors such as overeating, repetitive rituals, or a fascination with the same physical action repeated over and over. In some patients with FTD, language symptoms may be of greater concern over memory loss and many patients may demonstrate memory as an intact function. It is not uncommon for a patient to present with expressive language problems, but maintain his or her ability to understand word meaning. Over time, more language is lost until often the patient becomes unable to communicate altogether.

For those patients with FTD-related movement disorders, such as problems with equilibrium, safety can be a big concern. Patients may move more slowly and have body stiffness similar to the symptoms of Parkinson’s disease.
Lewy Body Dementia

In the same laboratory with Dr. Alois Alzheimer, a neurologist by the name of Frederick Lewy, MD, discovered a brain abnormality that we refer to today as Lewy body dementia (LBD).

The hallmark characteristic of this dementia is abnormal deposits of the protein, alpha-synuclein, which form inside nerve cells. The pattern of decline may be similar to Alzheimer’s disease as the core feature of LBD is a progressive cognitive decline which interferes with social functioning. Patients exhibit progressive changes in social behaviors, judgment, and problem solving, but may have relative sparing of memory decline in the early stages.

LBD shares many characteristics of a Parkinson’s disease dementia (PDD); however, LBD and PDD are each clinically defined syndromes. It is estimated that 10 to 15 percent of all dementia cases may be Lewy body dementia.12

Core features of the disease, per the third report of the Dementia with Lewy Bodies Consortium, include: cognitive fluctuations with variations in attention and alertness; visual hallucinations; and spontaneous features of Parkinsonism.13 Two core features are sufficient for a diagnosis of probable LBD while one core feature suggests possible LBD.

Other characteristics of this dementia include REM sleep disturbances and severe sensitivity to the side effects of neuroleptic drugs. Oftentimes, repeated falls, syncope, depression or abnormal SPECT/PET results, or abnormal MIBG myocardial scintigraphy are clinical symptoms.

The difficulty for caregivers is in the early appearance of behavioral symptoms as compared to Alzheimer’s disease, where patients often maintain socially appropriate behaviors in the early stages. Apathy is often identified in LBD patients and can often be interpreted by others as insensitivity or self-centeredness.14 In advanced stages, LBD and Alzheimer’s are more similar.15

The treatment for LBD generally parallels that of Alzheimer’s disease, although traditional neuroleptics and other dopamine blockers are often avoided while there is some circumstance for the use of antiparkinsonian drugs.16,17

Vascular Dementia

After Alzheimer’s disease, vascular dementia is the second most common type in the nation.18

It occurs when the vascular system within the brain becomes damaged and blood cannot reach the brain’s cells. The cells then die, leading to loss of cognitive function.

There are estimates that up to 41 percent of population-based dementia cases may have some vascular pathology. It is not uncommon for older adults to have a coexistence of both degenerative and vascular changes that affect cognitive abilities.19 Regardless of the pathogenesis of the vascular lesion, the result may be a dementia with behavioral changes or cognitive loss.20

In 2011, a consensus statement from the American Heart Association and the American Stroke Association (AHA/ASA) provided additional evidence of the importance of vascular contributions to dementia.21

As used by the AHA/ASA,
the term Vascular Cognitive Impairment (VCI) is often chosen to represent the syndrome of cognitive impairment associated with evidence of clinical stroke or subclinical vascular brain injury.

The diagnostic criteria available to physicians provide direction for establishing the link between the cognitive loss and vascular disease. There is growing research in the areas of cardiovascular risk, including genetic factors, lifestyle, depression, and physiological risk factors that also contribute to the growing literature on VCI. There is great opportunity to prevent or postpone cognitive impairment by identifying and reducing cardiovascular risk. Current literature in the area accept that many of the risk factors for stroke are also risk factors for Alzheimer’s disease.22

**Growing in Number**

Our elder population is growing, due in large part to better management of chronic diseases. (This, by the way, is not just an American phenomenon—the world’s population is aging at an unprecedented rate.23) Without a cure, the growing number of people expected to be affected by dementia is nothing less than staggering. This has wide-ranging implications for medicine, hospice, and families across America.

**New Rand Study in NEJM Reports Equally Staggering Costs**

A new study by Rand Corp., just published in the *New England Journal of Medicine*, reports on both the growth and costs associated with dementia care, along with the projected burden in future decades.

According to the researchers, dementia’s direct costs, from medicines to nursing home care, amount to $109 billion per year, compared to $102 billion for heart disease and $77 billion for cancer. Informal care by family members and others pushes dementia’s total costs even higher.

Read the full article online.
Here are just a few facts to consider:

- In 2010, there was an estimated 40.2 million Americans aged 65 and older. This number is expected to double to over 88 million by 2050. By the year 2050, all the baby boomers will have entered into our senior cohorts, pushing the percentage of our 85-and-older population from today’s 14 percent to over 21 percent.24 (It is also well documented that the oldest-old are often the ones who require additional caregiving, support, and healthcare.)

- Today, an estimated 5.4 million Americans have Alzheimer’s disease. The incidence of the disease increases dramatically with age so, by the year 2050, the number of people over age 65 with Alzheimer’s may triple. Women carry the highest risk of developing the disease, with an estimated lifetime risk of nearly one in five.25

**Advanced Dementia and Hospice**

Caring for a person with Alzheimer’s disease or another type of dementia poses unique problems, one of those being the presence and management of neuropsychiatric behaviors.26 These symptoms include personality changes; loss of communication; loss of inhibition; and agitation, anxiety and other mood disturbances. Ultimately in the later stages of the disease, neuropsychiatric behaviors are partnered with physical decline.

It is the behavioral problems, however, that are the most common and burdensome to caregivers. Behavioral disturbances, specifically aggressive behavior, have been identified in approximately 40 percent of people with dementia.

It is also important to note that the stages of dementia are not entirely predictable in all patients, but it is well documented that patients with end-stage dementia who have received supported services such as hospice may have fewer unmet needs.

There is a great range of behaviors that affect the patient’s quality of life (e.g., wandering, sleep problems, depression, delusions, irritability, anxiety, disinhibition), so healthcare professionals must utilize different measures to assess them. Ideally, the goal for any patient with dementia is the promotion of quality of life and well-being.27

Quality of life for people living with dementia is strongly influenced by communication and social relationships. Thus, it is fundamental to any caregiving experience that practitioners use techniques and skills that enhance communication and contribute to the patient’s daily joy.

It is common for patients with dementia to exhibit poor well being, either from physical pain and/or psychological distress.28 The deterioration of communication in most patients requires health professionals to use well-developed skills of assessment to ascertain the source of distress. The goals of care should be developed in partnership with a full care team that includes the family, the caregivers, and any previously reported preferences from the patients themselves.29
There should also be a partnership between pharmacological and nonpharmacological interventions to help address the multiple risk factors and symptoms associated with advanced dementia.\textsuperscript{30} The utilization of nonpharmacological interventions such as aromatherapy, music therapy, touch therapy, enhanced non-verbal communication techniques and spiritual activities have potential for addressing unmet psychosocial needs.\textsuperscript{31} The assessment of neuropsychiatric symptoms, coupled with quality care planning that includes nonpharmacological techniques, can make goals possible that address quality of life.\textsuperscript{32} Evidence is also mounting that the distress seen in advanced dementia when left untreated contributes to the poor health outcomes of the patients’ caregivers.\textsuperscript{33}

The use of hospice services among the dementia population has grown steadily in the last five years, including use among Medicare decedents with advanced cognitive impairments. For example, in 2001, only 14.4 percent of Medicare decedents with a dementia diagnosis received three or more days of hospice care. By the year 2007, that proportion had grown to 33.6 percent.\textsuperscript{34}

Palliative care and hospice can play a significant role in addressing physical, emotional, and spiritual distress during advanced dementia. Supportive programs that are based in a firm understanding of the clinical progression of the disease are more likely to provide the physical and emotional comfort needed at the end of life.\textsuperscript{35}

With the growing number of people living with dementia, there is a strong and compelling directive for all healthcare providers to help promote quality of life and reduce distress throughout the clinical course of these dementias.

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\textbf{References:}
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I am a classic extrovert, thriving off the energy from interactions. As such, when serving the spiritual needs of patients with dementia, it wasn’t long before I would become restless and fidgety like a five-year old pent up in the back seat of a car. I was anxious to be done with what I saw was an arduous task. I say this not because I’m proud of that behavior, but to gently invite others to be similarly honest about their own struggle. I also knew I was doing a disservice to patients, my agency and myself, and made a commitment to learn more about the disease. Thankfully, individuals who are experiencing dementia have been incredible teachers, and in this article I share what I have learned and come to treasure in the hope it will help you in your practice.

My Aha Moment

One night I stumbled onto a YouTube video of Naomi Feil, MSW, ACSW, engaging with dementia patient, Gladys Wilson who had her eyes closed and had been unresponsive for some time.

Feil, who is the founder of Validation Therapy, moved closer to Ms. Wilson, began to mirror her energy and movements, and noticed aloud that a tear was forming in the corner of Ms. Wilson’s eye. She was truly present with Ms. Wilson, entering her internal, withdrawn world. She was able to connect with Ms. Wilson in the time of this short video, so much so that Ms. Wilson opened her eyes and joined Feil in singing “He’s Got the Whole World in His Hands.”

This video clip certainly opened my eyes to dementia, and as I began to learn and grow, I was amazed at the worlds of these patients which had been previously unavailable to me. By really learning to see, hear and understand these patients, I became more comfortable, grounded, and present with them. I could spend more time being curious about finding the people who are still very much there.

Dementia 101

In Latin, dementia literally means “out of one’s mind”—dis means “away from” and mens means “mind.” But that is far from the truth.

Individuals with dementia may not engage with us as they once did, and often don’t conform to our comfortable patterns of interaction and behavior, but
they are still very much here with us. We simply get to learn to look deeper, within ourselves and within these patients, to truly see them. In order to engage in their world, however, we need to have a basic understanding of the disease.

With help from my physician and nurse colleagues, I began to learn the medical side of dementia. While Dr. Lena Smith provides comprehensive information in the preceding article, let me also share some of what I learned through the course of my own exploration.

According to Dr. Linda Tavel, the medical director for Odyssey Healthcare of Houston, dementia is not strictly one disease, but a constellation of symptoms. There are many forms and causes, often with different ways of presenting and varying trajectories. Below I describe five of them, but the most important thing to remember is that no two patients are alike—their behaviors and symptoms will depend on the location of the diseased tissue, and this can greatly influence how they engage with others.

**The Definitions**
The DSM IV (*Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*) defines dementia as the primary loss of memory (amnesia), combined with one of the following “As”: Aphasia (difficulty with spoken/written language); Apraxia (difficulty coordinating movements or manipulating objects); and Agnosia (inability to recognize objects and faces). Patients may also have problems with “executive function” or higher skills (i.e., goal-directed behavior).

Dementias are largely diagnosed by physical examination and an individual’s behaviors, rather than a blood or radiologic test. The symptoms also develop gradually. In fact, families often look back in surprise to see the path of the dementia’s progress.

While the various dementias may look different early in their course, at end-stage they have a common trajectory. Patients are bed bound or unsteady and prone to falling; have difficulty swallowing and speaking; and require assistance with everything, from personal hygiene to eating. They are also prone to recurrent infections, severe malnutrition, and decubiti.

How a person with dementia interacts with us depends on (1) where the “lesion” resides in the nerve transmission pathway (i.e. in the cortex which houses higher functions or in the connective tissue between brain areas), and (2) whether it’s located in the
frontal lobes (which control behavior and social functions); the temporal lobes (which are responsible for speech and spatial reasoning); or in the deeper structures of the brain’s more primitive areas (which deal with survival).

Briefly:

- Alzheimer’s disease is the most common form of dementia, and is known for its gradual onset and steady decline. This is the most prevalent form of dementia that we see in hospice.

- Vascular dementia is the second most common form, and presents based on where the “little strokes” occur, almost like a “stair step” trajectory. Sometimes patients with vascular dementia do not change or worsen over time, if the strokes themselves stop recurring.

- Lewy body dementia is a very different form of dementia where patients may have good memory early in the course of their illness. Hallmark signs are visual hallucinations, visual-spatial impairment, and a waxing and waning trajectory. This form of dementia can be mistaken for psychiatric illness or delirium due to its inconsistent course.

- Frontotemporal dementia occurs in younger people (i.e. has a rapid onset and steep trajectory). These patients may have behavioral issues—with emotionally labile, inappropriate behavior. A sudden personality change can be the first sign.

- About 40 percent of individuals with Parkinson’s disease and the related Parkinson’s Plus syndromes may also develop dementia late in the disease process, but their illness should not be confused with Alzheimer’s disease.

Having this medical information was critically important to me as a chaplain. While I don’t have to grasp the medical side of dementia completely, being informed enough to ask the right questions of my medical colleagues has enabled me to serve these patients better.

For instance, patients with certain frontotemporal dementia may lose their ability to speak, but will retain comprehension and memory longer, so we never assume they cannot understand us, even in the absence of verbal response.

On the other hand, the waxing and waning course of Lewy body dementia means we prepare to enter a very different world every time we engage with the patient. We must know this in order to help the patient’s family manage the day-to-day extremes associated with this disease course.

It also means that we do not document a patient with Alzheimer’s as being “conversant with us” because she accessed long-term memory centers and joined in saying “The Lord’s Prayer” or “Our Father” when, in fact, she can typically speak just two-to-three words.

Really Seeing: The Assessment

How then do we learn who the patients are, and develop a plan of care, especially if they cannot tell us? We ask them. We notice the pictures and notes around their room. We talk to staff who often have developed close relationships with them. And we ask their loved ones about historical information; the names of people in pictures; their work history and hobbies;
and their favorite music, foods, sights, textures, and smells. We also ask about important people in their life and significant stories that helped define them for good or for ill as well as their “love language”—how they best expressed and received love, felt valued, and knew they were safe.

Then we inquire about their spiritual journey from start to finish, asking their loved ones if there was “any particular faith tradition in which they were raised” (instead of “what church did they go to”). This can be a gentler, less indictment-filled way of assessing the spiritual path of the patient and family because, when asked about their earliest spiritual experiences, people often start at the beginning and tell the entire story, including all the transitions, triggers, land mines and baggage they have collected, and the moments that transformed and comforted them, giving them their spiritual strength.

By approaching the discussion in this way, we are not assuming it is a dominant U.S. religion or even any particular religion, nor are we expecting they’ve participated recently, in the midst of sickness and caregiving. We are simply allowing them to share “the rest of the story” that has rich information we might otherwise miss.

**Being Present: Engaging**

Once we know these things, there are practical, common sense, matters we often forget:

**GetGroundedBeforeEnteringTheirPresence**

Have you ever entered a patient’s room in a rush, already behind and needing to “get in and get out”? If we bring chaotic energy into the room with us, those whose “emotional thermostat” is not working will react to it negatively. Besides, how can we truly be with others when we are still working out the last case in our heads or thinking ahead to the two hours of documentation before us this evening? We must be present.

**Greet Them Warmly**

Greeting patients warmly can increase their sense of comfort and make us feel more familiar to them. But create a connection that feels right (and genuine) to you. Even those with the most severe cognitive impairment can smell a phony. One woman sneered at me when I approached her with “warmth” I didn’t feel in that moment. She knew! Pay attention to what works well, and what doesn’t—for you and for the patient.

**LimitExternalStimulation**

Consider going with the patient to a quieter place, asking
permission to turn off the TV, and closing the privacy curtain around his or her bed. Approach them slowly, quietly, and at eye level (to create an “equal with” and non-threatening synergy).

**Always Address the Patient First**
When I enter the room, I address the patient first, even if family is present (after all, it’s their room). I walk past the family, smile and say “excuse me,” walk up to the patient, kneel down, take their hand, and greet them. Even if they are unresponsive, I say “Hello Mr. or Ms. Smith. I’m Carla, the chaplain. I’m here to check on you and your family and see if there’s anything I can do to support you. I’m going to talk to them now.” And if I know it’s appropriate for the patient and family, I’ll say “If it’s okay, I’ll come back and say a prayer with all of you before I leave.” I then get up and address the family. It’s amazing to feel the difference in the room’s energy when I handle the interaction in this way.

**Shorter But More Frequent Visits May Be More Effective**
Shorter visits may overwhelm patients less since asking questions they can’t answer or can’t verbally communicate can be frustrating and could cognitively “overload” anyone.

**Wear a Name Tag With Large Print**
I have the requisite name badge with my photo, so the print is quite small. However, on the reverse side I have printed my name, title and organization in very large print. It’s also on a retractable clip, so patients can pull it close to read it as often as they want to clarify who I am.

**Always Treat the Patient With Respect**
If the patient had a title, use it, but then find out how he or she prefers to be addressed. Use familiar language or terms of endearment (e.g., honey, sweetie) only if the patient asks you to—and it clearly works for them. I cringe when I hear someone’s behavior described as “cute.” That’s a word we use for animals and children, not grown adults who spent a lifetime contributing to this world independently and doing amazing, if imperfect, things.

The patient may be in a brief and drooling, but he or she is still Ms. or Mrs. or Dr. or General or Reverend and, even beyond the title, is of immense worth as a human being. These patients are still the people they were before the dementia!

**Never Assume About the Nature of Their Relationships**
Caution volunteers and staff to never say, “Oh, your mom is so sweet!” We never know the whole story and must always remember that. It devalues the family and the struggles they have sometimes endured to assume they had a good relationship or were treated well by the patient. By making false assumptions, we miss opportunities to assist patients and their families with emotional and spiritual distress if we simplistically gloss over this aspect of care.

**Finally, Put It All Together**
Find ways to incorporate all the assessment information that was gathered—including music, faith symbols, prayers, poems, readings, and familiar activities—into your interactions and interventions. As I did this, I began to learn how familiar sights, sounds, smells, and even people can trigger deep, long-held memories in patients with dementia. For example, as one patient stroked the fur of my two border collies, he spoke the name of his favorite pet from long ago, and began to relax
and smile. Another patient, when handed fresh hay from the fields, began animatedly using words and gestures indicating he was, in his memory, back working on his own farm and appeared quite happy in those memories.

**What We Get to See**

Ms. W was non-verbal with staff. She sat one day in her wheelchair in the dining room, playing with her food, and humming “Take Me Out to the Ballgame.”

I walked in and stood a few feet behind her, listening, amazed to hear her make sound. When she stopped mid-song, I picked up where she left off, humming the next phrase. I stopped, she turned and looked at me for a long moment with an eyebrow raised, then hummed the next phrase of the lyric. She stopped, leaned toward me, eyebrow still aloft, and waited for me to pick up our duet. After we hummed the last line together, she sang the first part of “Shave and a Haircut”: DUNT da da DA da. And I replied “dunt DUNT!” It became our first conversation.

I discovered from her family that she was the pianist at her church for decades, so I learned her favorite hymns. I sang, she played the air piano, and then clapped and cheered after we finished. I never heard her utter a word, but we learned to communicate through the music she loved.

Then there was Mr. C. When he moved his fingers one way, I learned that he was tying flies as he once did for fly-fishing. When he moved his fingers in another way, I learned that he was reliving his life’s work in his architecture office. Knowing this, we located an old drafting table and placed some manila folders and notebook papers on it. He found great comfort in stapling, filing and drawing at this table, as if he were back in his office.

For Ms. U, moving her fingers in a certain way was a reflection of her wizardry at ten key. So by giving her an adding machine, she re-engaged in what had given her a sense of financial security, value, and meaning most of her life.

Research now shows that engaging patients with dementia in appropriate activities is associated with decreases in various forms of behavioral disturbances. (To learn more, see “Tailored Activities to Manage Neuropsychiatric Behaviors in Persons with Dementia and Reduce Caregiver Burden: A Randomized Pilot” in the *American Journal of Geriatric Psychiatry.*)

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Really Listening: Witnessing Pain

Increasingly, experts believe that unresolved developmental tasks and unrepaired trauma seek to be finalized at the end of life so we can transition from this world in dignity and peace. It just feels better to have dirty dishes cleaned and laundry put away before we travel. In the same way, Naomi Feil in The Validation Breakthrough (2002) discusses the Resolution phases of dementia that people may experience, and how to be with them during this time. I began to see this in my own patients as their significant stories of past woundedness surfaced in order to be resolved.

Those who cry out for help repeatedly are often moved to the end of the hall, medicated to calm down, or re-directed so they won’t bother anyone. But what if this is actually psychosocial or spiritual distress seeking to be heard, witnessed, and resolved? We are beginning to understand that at some point the individual may have felt unsafe and could not ask for help, or asked and wasn’t heard. So let us try to hear them now.

To do so, we must first find that still quiet space inside of ourselves that many of us find threatening and seek to avoid. Perhaps we fear we will not be enough or will not like what we find there. John S. Savage writes, “You can enter the pain of another only at the level you can enter your own.” So if we wish to really be with and see these patients and their pain, we are challenged to first be capable of sitting with our own. Then, we can sit quietly with them, whatever they may be experiencing or expressing.

We can take their hand and tell them, “It’s okay. You’re safe. I’m here. We’re going to get you the help you need.” It may take multiple sessions to connect with them and calm them down, but eventually, disturbances go down because they have been heard, the need has finally been met, and the trauma, long ignored, has been resolved.

I began to learn that behaviors we often write off as “nonsense” are actually a way that many of us use to cope with, mask, express, or resolve these issues. But dementia can rob people of their ability to communicate the pain in a way that is immediately understandable to the rest of us.

Consider the patient who crawls to the corner of her room, fussing with her bedspread and the boxes of tissues she has tossed onto the floor. When we talk with her daughter, we learn that the patient had previously dealt with her distress through obsessive cleaning.

Understanding this, I said to the patient, “My, you are busy.” She responded, “Yes, yes, yes, gotta make the bed, gotta make the bed, gotta make the bed…” and she was! It didn’t look to us like dignity, but it was her way of coping with distress, exactly as she always had. We were then able to explore what was distressing her, rather than insist that she get back into bed and stop making, what to us, seemed like a mess. As we explored her story with her family and found the sources of the long-term spiritual distress, we were able to offer words of assurance, rather than rob her of the space she needed to find resolution and dignity in her own way and time.

The stories go on. If only there was space to convey them. But this is a journey—for patients, their loved ones, our industry,
and our society. We must be patient, yet persistent. Because to deny them, to turn away because we aren’t comfortable, robs us all of great gifts. May peace and blessings be with us as we learn together.

Carla Cheatham is a spiritual care coordinator for Heart to Heart Hospice in Austin, Texas, and a member of the NCHPP Spiritual Caregiver Section Steering Committee. She is also the co-founder of the Texas New Mexico Hospice Organization’s Chaplain Development Committee (CDC) which provides training for spiritual caregivers in Texas and New Mexico. The trainings have proven so effective that Carla and members of the CDC now travel nationally to other hospice organizations to provide similar presentations.

Dementia can rob people of the ability to communicate pain in a way that is not immediately understandable to us.
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With your help, we fund post-graduate palliative care training for African nurses.

Upon completing their coursework, nurses will return to their community where their new knowledge will not only help ease the pain of their own patients, but will allow them to mentor and educate others; creating an ever increasing network of palliative care provision.

Go to: crowdfunding.fhssa.org choose “Make an Impact” and click the “Fund This Campaign” button.

FHSSA, formerly the Foundation for Hospices in Sub-Saharan Africa, is a 501c3 organization and an affiliate of the National Hospice & Palliative Care Organization (NHPCO) based in the US.
ehospice USA: 
A New Resource for Your Referral Partners

Last fall, NewsLine reported on ehospice—a collaborative “international” venture between UK-based Help the Hospices and hospice palliative care organizations around the globe.

ehospice is both a website and a mobile app, but with multiple country and regional editions that provide information and news relevant to the respective area or locale.

Last October, editions were launched for the UK, Australia, Canada, Africa, Kenya, South Africa and India, along with an International Children’s edition. Since then, several more editions have been introduced, including “ehospice USA,” which is being spearheaded by NHPCO and was just unveiled at the Management and Leadership Conference in late April.

While the look and feel of “ehospice” is common among all editions, the audience and content may differ, depending on the informational needs and gaps of each country or region.

For example, the content on ehospiceUSA is geared specifically for a hospice’s referral sources—the physicians, case managers, and healthcare professionals in your community who would benefit from up-to-date information about hospice palliative care and how it can help address their patients’ needs.

“The NHPCO website and its companion sites already fulfill the informational needs of hospice palliative care professionals, consumers and advocates,” said NHPCO president/CEO, Don Schumacher. “So we wanted to use this opportunity to help our members reach important constituents in their communities.”

Key stories now online include a summary of the stunning new research conducted by Mount Sinai; facts about hospice that everyone should know; and paying for hospice care.

Explore the site now—and be sure to bookmark and share it with your current and prospective referral sources:

http://www.ehospice.com/usa
Veterans Outreach Opportunity: 
Host a Screening of “Honor Flight, the Movie”

As many members may know, the Honor Flight Network is a non-profit organization that makes it a mission to transport America’s Veterans to Washington, DC to visit and reflect at their memorials. Top priority is given to World War II Veterans as well as to those who may be terminally ill.

Now a movie captures the significance of this gesture and the depth of gratitude felt by the Veterans who take these Honor Flights. This film documentary follows four living World War II Veterans as they embark on their trip to see the World War II Memorial, all while volunteers from their Midwestern community work behind the scenes to orchestrate a series of heartwarming surprises as their trip-of-a-lifetime unfolds.

To Host a Screening:
Visit the We Honor Veterans website for information on the two ways you can host a screening in your community—or download the PDF now.

If your organization is a We Honor Veterans partner, this is a great way to help maintain your partnership level or advance to the next level while raising awareness about your program and its commitment to Veterans.

To learn more about the film and watch the trailer, visit www.honorflightthemovie.com.
Two New Reports to Help Evaluate Your Hospice Operations

Every year NHPCO produces two Peer Reports to help providers evaluate their hospice operations:

- Peer Report—by Agency Size (from 1 to 9 patients to 200-plus patients)
- Peer Report—by Agency Type (freestanding, hospital-based, and home-health based).

What’s Covered
Each report contains 18 summary tables showing data on agency and patient demographics; staffing management and delivery; and payer mix, revenue and expenses.

How They Can Help
These reports are based on data submitted for NHPCO’s 2011 National Data Set (NDS) and its annual report, the National Summary of Hospice Care. They simply present the data organized by agency size and type (provider status) to make it easier for you to conduct an apples-to-apples comparative analysis of your operations.

For example, you can use data from these reports to help:

- Project fundraising revenue and expenses
- Assess length of stay
- Set census targets (if your agency is new)
- Evaluate volunteer utilization
- Provide your hospice board with industry perspective.

To see a sample of each report, visit the NDS webpage of the NHPCO website and scroll to Step 3/Reports.

To purchase the Peer Reports, send an email to nds@nhpco.org. (The reports are sold in sets: NDS participants pay $150 per set, and non-participants pay $300 per set.)

WIN A FREE SET OF PEER REPORTS AND HELP THE FIELD:

The deadline for submitting 2012 data to the National Data Set has been extended to May 15, so there’s still time to participate.

When you do, your name will be entered into a drawing to be one of three winners to receive these new Peer Reports.

NDS data submission is through the NHPCO DART system, which is accessed right from the NDS webpage of the NHPCO site. Your participation will make a difference. Please take time to submit.
In March, the National Center for Health Statistics released a report on “Trends in Inpatient Hospital Deaths: National Hospital Discharge Survey, 2000–2010.”

According to the report, there were 2.5 million deaths in the U.S. during 2010, compared with 2.4 million in 2000. In both years, about one-third of these deaths occurred in short-stay, general hospitals despite research that shows that most Americans prefer to die in their own homes.

Below is one of the tables from the report, showing the percentage of inpatient hospital deaths by first-listed diagnosis (i.e., the principal diagnosis or main reason for the hospitalization).

Table. Inpatient Hospital Death Rates in US by First-listed Diagnosis: 2000, 2005, and 2010

<table>
<thead>
<tr>
<th>First-listed diagnosis</th>
<th>2000</th>
<th>2005</th>
<th>2010</th>
<th>Percent change¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate per 100 persons hospitalized for diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2.5</td>
<td>2.2</td>
<td>2.0</td>
<td>-20</td>
</tr>
<tr>
<td>Respiratory failure</td>
<td>25.3</td>
<td>19.3</td>
<td>16.5</td>
<td>-35</td>
</tr>
<tr>
<td>Pneumonitis due to solids and liquids</td>
<td>17.4</td>
<td>15.2</td>
<td>13.6</td>
<td>-22</td>
</tr>
<tr>
<td>Septicemia</td>
<td>13.9</td>
<td>19.3</td>
<td>16.3</td>
<td>+17</td>
</tr>
<tr>
<td>Kidney disease</td>
<td>9.9</td>
<td>6.5</td>
<td>3.5</td>
<td>-65</td>
</tr>
<tr>
<td>Cancer</td>
<td>8.1</td>
<td>6.8</td>
<td>4.4</td>
<td>-46</td>
</tr>
<tr>
<td>Stroke</td>
<td>6.4</td>
<td>6.5</td>
<td>4.7</td>
<td>-27</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>4.9</td>
<td>3.3</td>
<td>3.3</td>
<td>-33</td>
</tr>
<tr>
<td>Heart disease</td>
<td>3.7</td>
<td>2.8</td>
<td>3.1</td>
<td>-16</td>
</tr>
</tbody>
</table>

Download a PDF of the complete report, from the CDC website.
Inadequate documentation of verbal (or oral) certification of terminal illness can be a reason for a denied claim or negative audit outcome.

The Medicare hospice regulations require that if the hospice provider cannot obtain written certification of the terminal illness within two calendar days of the election of hospice services, it must obtain verbal certification within that timeframe instead. A written certification must then be obtained and on file in the patient’s record before the hospice can submit a claim to its Medicare contractor.¹

What Should It Cover?
Because the verbal certification is standing in for the written certification, it must contain certain information that is included in the written certification, such as:

- A statement that the individual’s life expectancy is six months or less if the terminal illness runs its normal course;
- The Benefit Period dates that the certification or recertification covers;
- The name and credentials of the physician who provided the verbal certification;
- The name and credentials of the hospice staff member receiving the verbal certification.

The verbal certification should be obvious in the clinical record. While there is no official regulation that requires that it be separate from a patient’s plan of care (e.g., the 485 form), CMS has stated that it is their preference to see separation of these two pieces of documentation.

Is It a Physician Order?
The Medicare hospice regulations do not state if the verbal certification is a physician order or that it requires a physician’s signature. If a provider chooses to treat the verbal certification as a physician order, then the state regulations pertaining to physician orders must be followed.

References:
HPCO’s End-of-Life Online (E-OL) offers online courses that are convenient, efficient learning modules for staff and volunteers at all levels of your organization.

Here are a few of the recent additions:

• Hospice and Palliative Care, Simply the Best with Ira Byock
• Identifying and Addressing Traumatic Stress at the End-Of-Life with Therese Rando
• Shed for Success: How to Stay Alive and Thrive in the Midst of Turbulent Healthcare Change with Kathy Dempsey
• Pediatric Palliative Care Training Series - Module 7: Pediatric Palliative Care Symptom Management

Plus, Several on Volunteer Management and Leadership:

• Regulatory Matters for Volunteer Leaders with Judy Lund Person
• Do it Well, Make it Fun, the Key to Success in Volunteer Management with Ron Culberson
• Ignite your Leadership Potential with Claire Tehan
• The New Breed of Volunteer with Thomas McKee
• Volunteers: Exceptionalism in Care and Practice with Gary Gardia and Danae Delman

Check Out the New ‘A-Z’ Course List Too:

To easily peruse the range of courses available, visit the E-OL “A to Z Course List” on the NHPCO website and simply scroll and click on the offerings of interest.

The webpage about each offering shows the cost of the course, details about what it covers, and whether it qualifies for CE/CME.
Twenty-year old Laura Rozo, a student at the University of North Carolina, died on April 11, 2013 from stage IV rhabdomyosarcoma.

Laura, who was served by hospice during her final months, embraced living fully, every day, since learning of her illness in the summer of 2011.

“You don’t have to be diagnosed with cancer to claim your life,” she said, speaking before friends and colleagues at a UNC Conference in February. “Cherish what you have and make use of it.”

This was a message she wanted to share with as many people as possible. Watch the video of her remarks now—and please consider sharing it too.
Third Annual FHSSA Global Partnership Award Was Presented on April 25

Center for Hospice Care/Hospice Foundation of Indiana and the Palliative Care Association of Uganda are the 2013 Winners

The third annual FHSSA Global Partnership Award was presented to Center for Hospice Care/Hospice Foundation of South Bend, Indiana and Palliative Care Association of Uganda on April 25 during the National Hospice and Palliative Care Organization’s (NHPCO) Management and Leadership Conference.

The Global Partnership Award is an opportunity to recognize the outstanding efforts of a partner that went above and beyond the expectations of a partnership. The award winner is selected based on creativity in fundraising, partner collaboration, staff contribution and commitment, and community outreach and involvement. The award comes with a $500 donation to the African hospice partner.

“Center for Hospice Care/Hospice Foundation has shown what a tremendous impact one partnership can have. The creativity and commitment they have made to the Palliative Care Association of Uganda will have a lasting effect on the patients and families needing palliative care and also to the dedicated health care workers who work tirelessly with limited resources to provide that care,” said John Mastrojohn, executive director of FHSSA.

Center for Hospice Care/Hospice Foundation, which raised over $25,000 in 2012, partners with the Palliative Care Association of Uganda (PCAU). The review committee was impressed with CHC/HF’s award application on many levels, including their unique and creative fundraising efforts and involvement in advocacy efforts on the national level in Uganda, their dedication to finding a new home for PCAU headquarters, and their financial support for scholarships to train Ugandan healthcare workers in palliative care.

“Our FHSSA partnership has been rewarding and meaningful for our staff, our board and our volunteers. It has been our privilege to be partnered with PCAU. But it’s so much more than a partnership. For us, faraway places have come closer, the planet has become smaller, and our own hospice family has grown in the best ways possible,” said Mark Murray, president and CEO of CHC/HF.

Some of the 2012 highlights of this award-winning partnership include:

- **Okuyamba.** In collaboration with faculty and alumni of University of Notre Dame Film, Television and Theatre Department, CHC/HF created an award-winning documentary that offers a glimpse at the astounding challenges facing terminally ill people living in Uganda and the monumental issues PCAU encounters in its daily work. The film has helped increase world-wide awareness of the suffering of patients with life-limiting illness in Uganda and throughout Sub-Saharan Africa. CHC/HF has made the film available to hospices across the country to use in awareness-raising and fundraising efforts locally.

- **PCAU Building Fund.** One of PCAU’s top strategic priorities for 2012 was to find a sustainable office space for its headquarters. Proceeds from CHC/HF’s World Hospice & Palliative Care day event were directed toward acquiring that space.

- **Partner Visits.** CHC/HF provided funding for PCAU Country Director, Rose Kiwanuka to visit the U.S. In addition to meeting with CHC staff on a number of initiatives, Rose also attended NHPCO’s MLC near

continued on page 2
Washington, DC. In return, HF's COO Mike Wargo and volunteer Roberta Spencer traveled to Uganda to work on a number of partnership projects. Their visit included meeting with Members of Parliament to advocate for palliative care in Uganda.

- Scholarships. CHC/HF’s fundraising efforts have also supported two scholarship programs: The Clinical Palliative Care Course Scholarship and the Road to Hope Program, which provides financial support for child care givers to attend school following the death of a parent.

Mike Wargo, COO of Hospice Foundation noted, “It’s been said that pain knows no boundaries. Through our partnership with PCAU and through making our film Okuyamba available as an education and fundraising tool, we have also found that compassion and caring know no boundaries.”

FHSSA congratulates Center for Hospice Care/Hospice Foundation and PCAU for their outstanding commitment to their partnership and for making a lasting impact on palliative care in Africa.

**FHSSA Partnership Update**

**Two New Partnerships Were Formed in March**

We proudly welcomed the formation of these two new partnerships.

**Global Palliative Initiative and Mulanje Mission Hospital: Malawi**

This partnership is a landmark for FHSSA, as the inclusion of the Global Palliative Initiative (GPI), a Canadian healthcare workers group, will be the first Canadian-African pairing in FHSSA’s history. The GPI is a group of seven palliative care physicians and nurses from McMaster University in Ontario, Canada who have been seeking for two years an opportunity to partner with an African hospice. In March 2013, their search came to an end by partnering with Mulanje Mission Hospital (MMH) in Malawi.

Founded in 1928, MMH incorporates a palliative care staff of three full-time and five part-time members that works in conjunction with a team of 200 volunteers. The program provides outpatient, inpatient, home-based and pediatric palliative care. MMH has also recently been added as a site for clinical placements in palliative care for doctors and nurses who have had post-degree training in palliative care. With the aid of GPI, MMH has a wonderful opportunity to continue developing into a leader of palliative care in Africa.

**VITAS Delaware and Little Hospice Hoima (LHH): Uganda**

VITAS Delaware will be the 21st VITAS hospice program to join FHSSA. VITAS Delaware had considered joining FHSSA for some time, but only recently felt that they were ready to make the commitment. Now hospice staff and volunteers will begin the process of developing a strong relationship with their new African partner, Little Hospice Hoima (LHH).

Based in Western Uganda on the shores of Lake Albert, LHH started in 1998 as a satellite site for Hospice Africa Uganda (one of the first hospices in Africa). LHH’s palliative care program consists of 17 staff members who offer home care, consultation in the referral hospital, and a day care at the hospice and in the community. In addition, they have a large palliative care education program for volunteers and health professionals in Hoima and surrounding districts.
Results of the 2012 FHSSA Partnership Survey Reveal Impact on the Continent

330,000 People Were Touched by Partnership Programs

Every year, FHSSA partners are asked to fill out a survey in order to track the successes, failures, and challenges of the Partnership Program. The 2012 survey painted a picture of a program that continues to demonstrate significant impact in the development of palliative care in Africa. Last year alone, our Partnership Program touched the lives of over 330,000 affected by life threatening illnesses.

Who Took the Survey
Different surveys were developed for both African and U.S. partners. These surveys were distributed to all 92 FHSSA partnerships in January 2013. The U.S. and African surveys garnered response rates of 59% and 53% respectively. We thank all the partners who participated.

A Picture of Palliative Care in Africa
While the HIV/AIDS epidemic remains a significant problem for Africa, the impact of other diseases, most notably cancer, has been growing. Indeed, 2012 was the third year in a row in which the percentage of hospices identifying HIV/AIDS as their most frequent diagnosis has fallen:

Identified Primary Diagnosis of FHSSA African Partners 2010-2012

Impact of the Partnership Program in 2012
This year, FHSSA partners raised nearly half a million dollars to support thousands of African hospice staff, and volunteers provide needed services to hundreds of thousands of patients and their families throughout the continent. Below is a breakdown of those supported by the Partnership Program in 2012:

- Total Donations to be Wired Directly to Africa: $462,875
- African Hospice Employees: 2,134
- Hospice Volunteers: 5,183
- Hospice Patients: 66,000

In addition to the impact on service providers, the Partnership Program provided valuable collaborative support in numerous areas. The chart below demonstrates other areas where FHSSA U.S. partners were active.

Considering the support that is transferred between the partnerships, it is not surprising to see a high level of satisfaction with the program. In fact, almost 90% of African partners consider their partnership to be “important” to the operation of their organization.

While the partnership program has been important for the African partners, U.S. partners have also benefited. In fact, over 75% of U.S. FHSSA partners reported that the partnership had made an impact on their organization. This impact is seen in many different ways:

As demonstrated by the 2012 annual partnership report, the FHSSA Partnership Program continues to play a significant role in the development palliative care in Africa while also benefiting U.S. partners. As the face of palliative care in Africa continues to change, there is little doubt of the importance of the Partnership Program in its continued development.
One Vehicle Can Make a Big Difference in Zimbabwe

VITAS Innovative Hospice Care of the Inland Empire Raises Funds to Buy a Truck

One of the most significant challenges facing palliative care providers in Africa is lack of transportation. A large portion of African patients live in far-flung rural areas, cut off from public transportation or even roads. Thus, ensuring that health care workers are equipped with proper means of transportation is extremely important.

This situation certainly held true for Nyadire Hospital Palliative Care Program located in Zimbabwe. According to Dr. KM Tshiani of Nyadire, “Following up with patients and caregivers was difficult. Patients live in scattered directions in various different locations in villages.” The result of this scattering of patients was that a nurse could only attend to a few patients at a time. In a region where the need is so great, medical workers must be able to attend to as many patients as possible.

Two organizations came together to help Nyadire Hospital Palliative Care Program address this crucial need. Together, VITAS Innovative Hospice Care of the Inland Empire (a FHSSA partner) and the Nyadire Connection (a faith-based American non-profit organization) purchased a new 4x4 truck. Such a sturdy vehicle is necessary for the rugged terrain.

According to Tammy Shewell, a social worker at VITAS of the Inland Empire, they first identified the goal after a conversation with Dr. Tshiani about three years ago. In the subsequent years, the hospice conducted several fundraisers, including yard sales, raffles, and an auction raising nearly $24,000. This money was then combined with a large donation by the Nyadire Connection to cover the additional costs.

The impact of the new truck has already been felt. According to Dr. Tshiani, “After the vehicle came, the situation has completely changed…the nurses can now attend to many patients in a short time. Patients and relatives are happy to see a team visiting a patient with a new vehicle.”

Dr. Tshiani made note of one patient who was “bedridden for a long time due to AIDS, but became physically strong under our palliative care program. Then she suddenly developed psychosis, which made it difficult for her relatives to assist her, as she refused to come to hospital. With the vehicle, it was easy to reach her and integrate her in to a mental health program by a visiting mental health team.”

Host Okuyamba in Your Community

Create Awareness and Raise Funds

The Center for Hospice Care and their FHSSA partner, the Palliative Care Association of Uganda have created a multi-award-winning 30-minute documentary on palliative care in Uganda. They have teamed up with FHSSA to offer a great new way to build awareness and donations around your Partnership through an Event-in-a-Box.

Okuyamba follows the journey of Rose Kiwanuka, Uganda’s first palliative care nurse, as she travels throughout the country, training, supporting and encouraging the nation’s 120 palliative care professionals. This powerful documentary is a great tool to help build awareness of the need in Africa and how work is accomplished.

The Event-in-a-Box materials you will receive include the DVD of the film, Okuyamba, a How-To guide for hosting a screening, customized posters and self-mailer postcards, and template media requests.

“The Event-in-a-Box is a great new tool for our partners to increase community awareness and raise needed support for their partnership,” states, John Mastrojohn, FHSSA’s Executive Director.

Want more information on how the Event-in-a-Box can help your FHSSA Partnership? Ready to host your own screening? Visit http://www.okuyamba.org/
African Hospices Can Now Benefit from the National Hospice Foundation’s Run to Remember® Program

Ellen Green of Hosparus Inc. Raised Money for Shepherd’s Hospice in Sierra Leone

Ellen Green, Senior Director of Counseling Services at Hosparus Inc., which serves Kentucky and Southern Indiana, was the first person to take advantage of a new opportunity to raise money for an African hospice through the National Hospice Foundation’s Run to Remember® program. She ran the Carmel Marathon in Carmel, Indiana, on April 20, 2013. This was her first marathon.

Since 2009 Hosparus has partnered with Shepherd’s Hospice in Sierra Leone. Green used the Carmel Marathon to raise funds to support their sister hospice a continent away. “I have run five half-marathons in the past five years and I decided I wanted to try a full one. I know our sister hospice in Sierra Leone has many needs. I thought raising money for Shepherd’s Hospice would provide some additional motivation and inspiration for me as I continue my training,” said Green.

Shepherd’s Hospice is headquartered in Sierra Leone’s capital city of Freetown and has a clinic in a rural part of the country. In February, they broke ground on a new 10-bed clinic and hope to have it built by the summer of 2014. Hosparus hopes to raise a total of $15,000 to help furnish the new clinic with medical equipment. With a $15,000 investment, Hosparus can work with the nonprofit Supplies Overseas to ship approximately $150,000 - $200,000 worth of equipment to the Shepherd’s Hospice.

A policy change for 2013 at the National Hospice Foundation’s Run to Remember program means that runners and walkers who are raising money for hospice care can now designate 50 percent of their proceeds to go to an African hospice. In the past, such designations were restricted to U.S. hospices.

Run to Remember is an easy way to raise money. All a runner (or walker) has to do is 1) register for a race (anywhere/any place) and then 2) sign up with Run to Remember to gain access to online fundraising tools. Hospices do not need to host a race. To learn more, visit www.fhssa.org/RTR or contact Jeremy Taglieri at 703-647-5172 or jtaglieri@fhssa.org.

Another Partnership—Another Friendship

In March, a team of staff and volunteers from Samaritan Healthcare & Hospice of New Jersey visited their FHSSA partner, Kawempe Home Care in Kampala, Uganda. The team, which included a physician, two social workers, two nurses, a massage therapist and two volunteers, travelled 8,000 miles to see firsthand the impact that their FHSSA partnership has had. The visit had a significant impact on the visitors. Upon returning, Joanne Rosen commented, “We are more enthusiastic than ever about increasing our support for [Kawempe’s] mission.

Every year FHSSA partners engage in exchanges just like this one. As the team from Samaritan discovered, such visits provide a unique opportunity to develop a partnership based on the goal of, “idea-sharing, professional exchanges, technical assistance, educational development and organization support.”

If you are interested in learning more about how to become a FHSSA partner, please visit our website at www.fhssa.org or contact jtaglieri@fhssa.org.
Crowdfunding News

FHSSA Second Campaign Focuses on Nursing Scholarships

“Social fundraising” or “crowdfunding” is a powerful new tool that describes an effort by individuals who network and pool their resources to support a cause, or individual projects within a larger mission. In December, FHSSA started our first crowdfunding campaign, which focused on raising support for FHSSA’s Conquering Pain project.

The current FHSSA campaign is called Make an Impact and can be viewed at http://crowdfunding fhssas.org/campaign/detail/974. This $10,000 campaign will provide scholarships to African nurses for post-graduate training in palliative care. Millions of people in Africa suffer in pain from terminal illnesses such as HIV/AIDS, but there are too few medical workers trained in palliative care and pain management to help them. This campaign will provide funding for up to five nurses to receive post-graduate training in palliative care training. In Africa, nurses are also a primary source for medical education and mentorship for students, patients, families, and community health workers. The impact of a nursing scholarship goes far beyond the education of the nurse, and results in an expanding network to continue to promote and provide essential pain relief to those suffering throughout the continent.

In Africa, nurses provide the majority of health care, making it essential to ensure that they are properly trained in palliative care. This scholarship pays it forward. One trained nurse in palliative care will educate and train additional workers and family members, resulting in a growing network of palliative care service provision.

To help meet the demand for educated nurses, FHSSA and the African Palliative Care Association (APCA) created the African Palliative Care Nursing Scholarship Fund which provides scholarships for nurses to receive post-graduate palliative care training. In Africa, nurses are also a primary source for medical education and mentorship for students, patients, families, and community health workers. The impact of a nursing scholarship goes far beyond the education of the nurse, and results in an expanding network to continue to promote and provide essential pain relief to those suffering throughout the continent.

“Even one dollar can have an impact when you’re working together to make a profound difference for people in Africa who are struggling with illness and pain,” said John Mastrojohn, executive director of FHSSA. “Our crowdfunding site is a great way to donate, share among friends and family and know specifically how your contribution will be used to make a difference.” Visit crowdfunding fhssas.org to learn more about this new tool and to see the current projects using crowdfunding.

Any U.S. FHSSA partner who wants to raise money for a specific project for their African partner can also take advantage of FHSSA’s crowdfunding web platform. Thus far, FHSSA and our participating partners have raised over $11,000. If you would like to learn more about how to set up your own crowdfunding campaign, contact Jeremy Taglieri at 703-647-5172 or jtaglieri@fhssas.org.