Raising Funds for Your Hospice:
Two Ways to Attract More People to the Table

Working smarter is more important today than ever before as staffs are shrinking and needs are greater. And, certainly, we get “more bang for our buck” when our philanthropic initiatives are targeted toward individuals and businesses that, based on demographics and past behavior, are more likely to provide support.

When it comes to a service like hospice, however, with the potential to resonate with the vast majority of Americans, it is important to complement our targeted efforts with those that can help us attract a much wider range of donors. This article shares two ways to do this — through Giving Circles and Bequests.

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In 2000, while attending the Association for Healthcare Philanthropy’s International Educational Conference in Boston, the work of the Saint Alphonsus Foundation caught my attention. Its staff was presenting on the Saint Alphonsus Women’s Healthcare Fund, an initiative that allows women to make charitable contributions and actively participate in the granting of funds. As I listened, I began to see how this concept, known also as Giving Circles, might be an excellent fundraising strategy for those of us in hospice.

Giving Circles are a form of philanthropy where groups of individuals make a gift to a fund and decide together how the pooled funds should be used. Giving circles may focus on a broad range of interests, or they may be specific to one project or organization. Giving Circles also seek to increase their members’ awareness and engagement in the cause.

The seed that was planted at that conference came to fruition in 2004, when my organization (then Hospice of Lancaster County) launched its Women’s Giving Circle.

Over the past nine years, the Circle has grown from 24 founding members, who were recruited based on their interest and commitment to hospice, to more than 70 members, who together have contributed more than $200,000 to 56 different programs of the organization.

As Margaret Mead once said, “Never doubt that a small group of thoughtful committed citizens can change the world; indeed it’s the only thing that ever has.”

**Why Just Women?**

Certainly a Giving Circle can be comprised of both men and women. But research makes an interesting case for targeting your efforts to the women in your community.

For example, Bank of America/Merrill Lynch’s *2010 Study of High Net Worth Philanthropy* revealed some significant differences in the charitable giving behavior of men and women.

Findings showed that in nearly 90 percent of high net worth households, women are either the sole decision maker or an equal partner in decisions about charitable giving. Other key findings showed that women:

- Spend more time on due diligence before making decisions about giving to a charitable organization;
While I often use this column to update you on what is happening here in Washington, let me say, first and foremost, that we are very aware of the difficult issues that many providers are facing — from a decline in hospice censuses to some significant financial hardships that are due, in large part, to Medicare’s more onerous compliance requirements.

Please be assured that we are not only aware of the many issues, but are working to ameliorate those that we can. So I ask for your continued trust in us as we work to address them strategically, in concert with the Hospice Action Network and its very talented team of lobbyists.

On a related — and quite positive — note, the 2013 Advocacy Intensive that is taking place just blocks from Capitol Hill on July 29 and 30 is looking to be a very productive event. As we go to press with this NewsLine, more than half of the registrants are clinical staff — which was our goal. One of the primary purposes of this event is to convene a small but diverse group that could share the stories of hospice with members of Congress, so having good clinical representation is key. We are deeply appreciative to the hospice leadership and staff who are attending — and I will be certain to provide more details about what was accomplished in next month’s message.

Looking ahead, I hope to see many of you in late September at the Clinical Team Conference in Kansas City. Note too that the NHPCO board will be holding its next scheduled meeting in conjunction with the conference, including the always-helpful issues session where current changes and trends that are impacting the field are discussed. In fact, I hope you review the “Geographic Area Updates” that are emailed to members after board meetings. These emails, prepared by the NHPCO board member who represents your geographic area, are an excellent way to see the many ways in which your feedback is being recognized and addressed. (All “GAR Updates” are also available in the Press Room on the NHPCO website)

J. Donald Schumacher, PsyD
President/CEO
• Expect a deeper level of communication with the organizations they support;
• Place greater importance on the efficiency and effectiveness of the organization, and hearing about its impact on their gift; and
• Want to be actively involved with an organization and its mission, with volunteering being among their most important motivations to give.

More About Our Circle
Women of all ages — from 30 to 90 — participate in our Women’s Giving Circle, providing a rich network of relationships.

These women donate $500 annually by October 31, and may then vote on which projects to fund at the Circle’s Annual Meeting in November.

The pooled contribution is awarded as one or more “grants,” and must go directly toward Hospice & Community Care programs with the goal of enhancing and strengthening our hospice services.

For example, in its first year, the Circle used its pooled contributions of $12,000 to fund a Pediatric Palliative Care Conference for physicians, nurses, nurse practitioners and others who care for pediatric patients with serious illness. [To learn more about the 56 programs the Circle has funded since 2004, see our report on funded projects.]

While our Circle decided on a $500 annual contribution level — since it’s significant enough to have impact yet affordable enough for an individual donor — other organizations have chosen both smaller and larger amounts. The choice really depends on the demographics of your community and your philanthropic goals.

Committee Structure and Roles
The Circle has a Steering Committee that is comprised of a Circle chair and the chairs of three committees: Membership Committee; Education Committee; and Project Research & Awards Committee. Committees meet a few times each year, with each reporting back to the Steering Committee and providing periodic updates at Circle events.

The Membership Committee actively works throughout the year to continually recruit new members, with one-to-one recruitment being the most effective method. A Valentine Tea is held each February as a social and networking event, and draws new members into the Circle early in the year. A Wine & Cheese Networking Social is also planned to appeal to the wide range of ages, interests and schedules of prospective members.
The Education Committee plans and develops a Spring Education Program that focuses on philanthropy or a specific Hospice & Community Care program. Members often invite prospective members to attend as a way of introducing them to the Circle and Hospice & Community Care. This year’s event, which was held in May, featured a panel of hospice leaders who provided an organizational ‘state of the union,’ including a discussion on the impact of sequestration and Medicare reimbursement cuts.

The Project Research & Awards Committee has the key task of reviewing funding request proposals submitted by hospice staff. The process begins in the spring, with the proposals due by early June. This Committee then meets two or three times during the summer to evaluate the proposals. The Project Research & Awards Committee narrows down the proposals to those they will present to the full membership.

A Project Proposal Meeting is then conducted jointly by the Project Research & Awards Committee and Steering Committee in September. Committee members hear directly from hospice staff members who have submitted proposals. This gives the staff the opportunity to share their vision and passion for a specific area of need, and the Circle members the chance for direct interaction with those who are providing care and support to patients and families. While Circle members receive a detailed, written summary of each program or project, this face-to-face interaction is an excellent way to educate and engage them. Members of the Circle then have between September and November to evaluate the programs and projects proposed for funding, and to make their decision on those which they would like to see funded.

Final selection is conducted through a formal voting process that takes place at the Circle’s Annual Meeting in November. The Annual Meeting also serves as a social and networking event at which time the Steering Committee provides updates on the Circle’s activities. Absentee ballots are available for members who are unable to attend the Annual Meeting. Votes are counted during the Annual Meeting, after which time an announcement is made to the organization’s leadership and staff who submitted proposals.

Funding is provided for the following calendar year and those staff members who have

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received funds must complete a progress report for their projects. Updates on funded programs and projects are also provided to the entire membership during Circle meetings and events, and via an annual bulletin that is distributed each summer.

**Establishing a Circle at Your Program**

Women’s Giving Circles are not without challenges, and do require management and staff coordination. Ongoing recruitment of new members is paramount, as evidenced by Hospice & Community Care’s member retention rate of 47 percent. Since 100 percent of the funds are put back into hospice-related programs, there is also a small budget for marketing and event expenditures. Monitoring of grants made by the Circle must also be done to ensure that the funds provided are spent during the calendar year.

Based on our experience, it has been well worth the time and commitment required. In addition to raising more than $200,000 in nine years, our Circle has brought a new level of philanthropy to the organization in which new donors have become engaged in our mission and have gone on to become major donors of the organization. This profound and impactful ‘ripple effect’ is, in turn, helping us meet the end-of-life care needs of our community.

Bonnie Jess Lopane has served as Hospice & Community Care’s vice president of development and community relations since 1997, and has been with the organization since 1996. She has 26 years of experience in nonprofit healthcare development, marketing and public relations, and is a member of the Association for Healthcare Philanthropy. She also serves on the Development/PR/Marketing Steering Committee of the National Council of Hospice and Palliative Professionals.
Bequests

By Heather Slack-Ratiu, CFRE, National Hospice Foundation, with Nick Buchholz, Cornerstone Hospice & Palliative Care Foundation

Simply put, a bequest is the act of giving personal or real property by will and is something anyone with “anything to give” can do. But we also know it is much more than that.

An individual’s will is about values — their values. It’s not a mere transaction. And two particular bequests that were made to hospice are an excellent reminder of this.

“Vera and Alfred”

Cornerstone Hospice and Palliative Care is a non-profit hospice program, with a daily census of 800-plus patients and a service area that spans seven counties in Central Florida.

In 2012, its Foundation was notified that Vera and Alfred Reetz had died (on January 8 and January 21 respectively), and had bequeathed their entire $1.3 million estate to the hospice — its single largest donation on record.

In this case, Cornerstone was the fortunate recipient because the Reetzes not only valued hospice care, but had a direct connection with the organization.

Alfred had worked as a nurse for Hospice of Lake and Sumter County (the forerunner of Cornerstone) from 1988 to 1996. Vera, who was also a nurse, became a patient of Cornerstone during the final stages of her illness.

While the Reetzes had shared their intentions with the Foundation in 2009, they never shared the size of their intended gift and no one would have imagined it would be so significant. The Reetzes were known to live simply and frugally, never wanting to waste a thing.

Alfred liked to buy and sell stocks online while his wife gardened indoors. Together, they completed crossword puzzles and doted on Bunny and Patsy, their two beloved Weimeraner dogs. Trips to Australia were their one pricey pleasure.

The Foundation is using the couple’s gift to support a range of programs, including grief counseling, Pet Peace of Mind, and the Veterans initiative, Cornerstone Salutes!

Together with this gift, the Cornerstone Foundation has received over $5 million in gift expectancies over the past seven

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years despite having a relatively small team — a part-time planned giving director and three Planned Giving Committees staffed by volunteers.

“L. Evans”

In 2012, the National Hospice Foundation (NHF) also received some unexpected news from the attorney who was administering the estate of Ms. L. Evans. While Ms. Evans did not have any previous direct connection with NHF or NHPCO, she had bequeathed a $100,000-plus gift to the National Center for Care at the End of Life.

As NHF shared in the December issue of Giving Matters, Ms. Evans led a rather intriguing life for the CIA. Through her attorney, NHF learned that she was gifted in linguistics and fluent in four languages, and had spent most of her life in Europe during World War II, the Korean conflict and the Cold War. She particularly loved Paris and enjoyed spending nearly every summer there. She had even related stories of working undercover, which included brushing shoulders with the likes of the King of Spain.

In 2008, roughly three years before her death at the age of 89, she made plans with her attorney to provide distributions to three charities, one of them being her generous gift to support the National Center. Staff learned that she was served by hospice during the last week of her life and “knew of hospice” through her work as a hospital volunteer. This was an unexpected gift from an unusual woman who had learned through her life experiences that hospice was special and worthy of her support.

The Takeaways

While it is always strategic to invest time and resources toward philanthropic initiatives aimed at those most likely to give, make sure your general philanthropic messaging also encourages individuals to remember your organization in their wills — because you never know what their life experiences may have been and if that messaging might prompt a planned gift. It takes minimal staff time and cost and could mean a future gift.

As part of that messaging, here are a few tips:

1. Make available sample tax language in all printed and online giving materials to assist individuals in remembering your organization in their wills. For example:

   “I give and bequeath to __________, a not-for-profit organization incorporated in [state], with the business address of __________, and with a tax identification number of __________, [describe either the gift amount; percentage; or rest, residual and remainder of estate].”

Of Note

Giving rose to $316.2 billion in 2012, up 3.9 percent from 2011 (or 1.5 percent after inflation), according to the latest Giving USA report from the Center for Philanthropy at Indiana University.

Donations from Individuals accounted for the most (72%), followed by foundations (15%); bequests (7%); and corporate giving (6%).

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2. Tell the story of a donor who made a bequest and share the impact of the gift on your organization.

3. Invite current and future donors to consider making a “legacy” gift (i.e., a bequest made to honor loved ones or recognize their family name).

4. Work together with the donors to learn how they prefer to have their gifts recognized or celebrated.

5. Be mindful of ways to tell your story every day!

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Heather Slack-Ratiu is the director of major and planned gifts for the National Hospice Foundation, the philanthropic arm of NHPCO. [To learn more about NHF’s funding opportunities to advance hospice care, visit the NHF website.]

Nick Buchholz is the executive director of the Cornerstone Hospice & Palliative Care Foundation.

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Make sure your messaging encourages people to remember your organization in their wills...
Raising Funds and Friends Through 2 NHF Programs

One of the strategic goals of NHPCO affiliate, the National Hospice Foundation, is to help hospice providers raise funds and additional supporters for their own programs. Here are two such opportunities to be aware of — and consider.

Run To Remember®

This program provides individuals with an incredibly powerful way to honor loved ones who have died while also raising money to support hospice. And all they have to do is run or walk in a distance race — at their own pace!

How It Works

There is no one single “Run to Remember” race. Participants are free to select any event they want to enter, be it in their hometown or in another city.

Once registered for a race, participants are then asked to register on the Run to Remember website (registration is free). Once they do, they can access free training tools and fundraising support, and will receive a Run-to-Remember t-shirt customized with the name(s) of their loved one(s) on it.

As part of the registration process, participants can designate a local hospice of their choice to receive 50 percent of the proceeds they raise. (NHF receives the other 50 percent for support of national initiatives to advance hospice.)

Walkers are welcome as are recreational and experienced athletes. What draws everyone together is a passion to support hospice and a commitment to embark on a physical challenge.

Putting It to Use in Your Program

There are two ways for you, as a hospice provider, to take advantage of the program:

1. Put together a team of runners to all do the same event together (either through a team fundraising page, or individual fundraising pages).

2. Use all of your communication channels to alert your constituents that, through Run to Remember, they can run (or walk) any race of their choice to support hospice. This is also an excellent way to reach individual runners who may be unfamiliar with hospice, but are happy to run for a good cause.
Note too that each year, Run to Remember participates in “spotlight” races. For these races, it recruits teams of runners, has a presence at the race Expo, and in some cases obtains “charity bibs” (a great benefit at popular races, such as the Marine Corps and Chicago Marathons).

To learn more, visit the Run to Remember website. For-profits, there are ways you can benefit too — learn more!

**How It Works**

With a $500 registration fee (to help sustain the Fund), hospices can receive up to $1,500 in funding for each request, subject to an online submission process and review.

To learn more, visit the NHF website.

**Lighthouse of Hope Fund**

NHF launched this program in the spring of 2013. It provides funding to support hospices in their work to make a patient and family’s remaining time together as meaningful and memorable as possible. This could mean funding support to help bring distant families together or to fulfill a patient’s long-last wish (like going fishing with a grandson, or enjoying a special meal at a favorite restaurant).

**FHSSA Partnership Program: Another Way to Connect With New Supporters**

The mission of NHPCO affiliate, FHSSA, is to “build partnerships to enhance compassionate care in Africa.” Toward this end, the FHSSA Partnership Program facilitates partnerships between U.S. and African hospice providers.

Today, more than 80 partnerships have been established — and the benefits to each organization are wide-ranging. U.S. providers have remarked on how their partnership has energized and united their leadership and staffs as they work together in support of their African partner. Others have noted how their work as a partner has helped raise their organization’s profile within their own community and has widened their circle of supporters.

To learn more about the Partnership Program, visit the FHSSA website.

Be sure to also see Event-in-a Box, an opportunity to host a screening of the award-winning documentary, Okuyamba, and connect with new friends and supporters in your community.
Congratulations on taking your place alongside some of the most dedicated people you’ll ever be privileged to know.

As some of you may be aware, I began my hospice journey almost 18 years ago when Dixie Beyer, FHN Hospice’s founder and first director, was the initial recruiter and trainer of the organization’s volunteers. As it happened, I was her first volunteer and I’ve always considered that “calling” to be a wonderful turning point in my life. I hope it will be the same for you.

We are all part of one unit — the hospice interdisciplinary team — and we all strive for the same results: To provide patients and their caregivers with the best that we have to offer through training and experience. Your training will be ongoing as you attend ‘in-services,’ and that’s important. But, perhaps more important is what you experience as you confront new and often challenging assignments. So let me share some advice, based on what I have learned.
Every time you enter a new patient’s home, think about what an honor it is for a burdened caregiver to entrust us to take their place, be it for a trip to the grocery store or lunch with friends. We volunteers are the “cavalry” that hospice sends off to provide respite for a person who can’t abdicate their responsibilities lightly.

I would characterize assignments as “significant” or “insignificant.” During the insignificant — or less demanding — assignments, the patient may sleep throughout your visit, and you will have the time to read a book or flip through a magazine. You’d like to feel vital, but the one who really needs you there is the caregiver. Then there will be more “significant” times when the patient is alert and wants the comfort and reassurance that you, indeed, are right there for them. These assignments require that you reach a little deeper inside yourself to present that aura of calm and a look that says, “I’m in no hurry; I’m just here for you.”

In either situation, be assured that the caregiver appreciates that you, a stranger, is giving your time to better their day or evening — and allowing them to feel “normal again” if only for a brief time.

That said, being a volunteer doesn’t mean accepting every assignment. Not all assignments are a good fit, and you will probably know that in the first visit. There will also be times in your personal lives that require you to say “no,” and that too is to be expected.

Over time, you will also come across people who say, “I think you looked after my father.” That’s a powerful way to be remembered.

As a hospice volunteer, I have walked through many doors — but always from the outside to the inside. Now I find myself on the other side of the door.

My mother lived a mostly healthy life until age 94, and I naturally assumed I’d at least match that if not surpass it. Imagine my surprise when, in early February of this year, the little cough I had developed in October was diagnosed as stage 4 non-small cell lung cancer. It had returned after 10 years.

The first week of such a diagnosis is almost unbearable. Could it possibly be that I will be parting from my husband of almost 53 years, my children and grandchildren, even my sweet dog who won’t know where I’ve gone? It seemed that electric currents surged through my body every few minutes. A friend had given
me a card on a little stand that simply said, “Courage is fear that has said its prayers.” I must have repeated that statement and the Lord’s Prayer 100 times during that first week.

I received my diagnosis while wintering in Florida, and there I received nine of 35 radiation treatments and one chemotherapy treatment (of a proposed four-month treatment plan). Neither treatment guaranteed a positive outcome; however, both resulted in a fast decline of my strength and the will to live.

After much thought, I opted to discontinue both treatments and return home to Illinois, and to my hospice and the amazing people who make it what it is. I thought that I was coming home to die, I was that ill. My daughter and I arrived in Freeport at 5:30 p.m. on a Friday, and by the next morning I was officially enrolled in hospice. Everything has gotten better since then. With proper medication and unfailing support, I have just had a period of amazing quality of life.

Over my hospice career, I have watched many people pass from life to death over a matter of weeks and months. I feel blessed to have so often been on the sidelines, learning that death is not a monster lurking in a corner. It is the natural end of the birth process, sometimes coming sooner rather than later. Death can be so gentle you fail to notice that it has entered the room. In October I was doing an 11th hour visit, sitting just about three feet from the patient while her husband watched football in the living room. I was reading from my kindle, but looking up every few minutes to check the rise and fall of her blanket. On one such look-up, I was startled to see what I thought was an optical illusion — the blanket had ceased its gentle rise and fall. I looked again, and then put my ear to her mouth to listen for a sign of breath. There was nothing. But, I thought to myself, she was just here! So gently did she go.

Having a disease like mine is a blessing. My family and I have time to plan, a luxury denied to many people. My “ducks” are getting in orderly rows.... And, after years of Curves and Weight Watchers, I am now eating whatever I want, whenever I want – and as much as I want! I am managing my disease, it is not managing me! Some time ago I also wrote my eulogy; after all, who knows my life better than me!

Years ago I bought a book entitled Christian Caregiving — a Way of Life. Recently, I rediscovered it on the bookshelf and have read a bit of it each day, usually in the wee-small hours of the morning as I have very random sleep patterns. While we may have different views on faith, I found the simple premise of the book illuminating. As newly commissioned “caregivers,” I want to share it with you: “Care to the extent you are able; do what you can when you can. But remember that only God can provide the cure.”

Welcome to our club!
ehospice is a globally run news and information resource committed to offering the latest news, commentary and analysis from the world of hospice, palliative and end-of-life care. ehospice is a collaborative venture, with different editions developed for many nations across the globe.

ehospiceUSA is a free resource powered by NHPCO that has been created for a specific target audience—hospice referral sources. Any professional that may be caring for or supporting patients and families who may be appropriate for hospice will find useful information on ehospiceUSA.

NHPCO hopes that providers will share ehospiceUSA as a resource that will be helpful to the referral sources they work with in their communities across the country. Find this new resource at:

www.ehospice.com/usa
Spiritual care has been a strong component of hospice care since its medieval inception. The very first hospices were developed during the Crusades at a time when monasteries were centers for healthcare. The purpose of hospices (from the Latin word *hospes*, meaning to host a guest or stranger) was to provide care for sick pilgrims and crusaders journeying between Europe and Jerusalem.¹

Dame Cicely Saunders is credited with founding modern hospice in the 1960s. Saunders — who was trained as a nurse, medical social worker and finally a physician — felt the need for a system of healthcare professionals who work together to treat the “total pain” of the dying — “a complex of physical, emotional, social, and spiritual elements.” In 1996 she wrote:

> The advances in pharmacology and the new technologies are not the whole story. At our preliminary training school we were taught that we were host to our patients and their visiting families. It was also taken for granted that we would join in ward prayers morning and evening and carry out ‘last offices’ with reverence and respect. Life has changed greatly in over 55 years, but people’s needs, though expressed differently, remain beyond the strictly physical.²

In the United States, inspired by the works of Saunders and Elisabeth Kubler-Ross, a group of social reformers began an initiative to research and reform care for the dying. In 1971, a Hospice, Inc. steering committee worked on developing a statement of philosophy and essential components of hospice care. Members of the committee agreed on three assumptions: (1) that hospice is a “total community” which includes patients, families and staff; (2) that a hospice facility would be structured to provide socialization and community involvement, and (3) that hospice would provide an interdisciplinary approach, where professional roles would be flexible in order to allow for staff to “substitute” for one another and to “call on each other

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¹From the NCHPP Spiritual Caregiver Section*

*The National Council of Hospice and Palliative Professionals (NCHPP) is comprised of 15 discipline-specific Sections that represent the staff and volunteers who work for NHPCO provider-members. To learn more about this NCHPP Section, visit the NHPCO website.*
for help.” A group of scholars comprising the International Work Group on Death, Dying, and Bereavement further defined hospice as the “collaboration of many disciplines working as an integrated clinical team,” with clinicians in differing disciplines being equal partners in the patient’s care.3

For the past several years, some hospices have been shifting to a shared-care model. Under this model, hospice chaplains have been called upon to complete tasks outside their usual domain, such as conducting simple physical assessments (for level of pain and function), delivering medical supplies, providing instruction about the dying process, and requesting medication refills.

The chaplains’ participation in the physical dimensions of care has colored the way in which patients view and relate to them. Since the term “chaplain” is not part of many people’s usual vocabulary, patients often struggle to come up with terms to better identify their hospice chaplain to themselves and others. One particularly interesting term came from a hospice patient, who, upon seeing me arrive in her home, said to her friend, “The preacher-nurse is here.” Such a term exemplifies the way in which patients understand and accept a chaplain’s evolving role in the healthcare setting.

**A Unique and Necessary Role**

Some chaplains have voiced the concern that moving toward a clinical approach to spiritual care may take away some of the distinctive characteristics of our calling. Those who oppose utilizing chaplains in clinical roles may fear that the sacred element of a pastoral conversation may be missed in favor of standardized assessments and interventions. While this is a valid concern, in my experience as a chaplain, attending to the patient’s physical dimension of care has resulted in the following benefits to patients and families:

- When I take initiative in discussing medical or physical needs with patients, it empowers or frees them to explore physical symptoms which may be closely related to spiritual sources of distress.

- My acknowledgment of the patient’s physical needs affirms the sacredness in the physical elements as well. In other words, I communicate to them that their bodies matter and are inherently connected with their spirits.

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Having chaplains participate in treatment plans by assessing and reporting symptoms also allows for chaplains to fully participate in the creation and delivery of the patient’s plan of care.

This last benefit is particularly important because chaplains can play a unique and necessary role in addressing physical symptoms of patients. Pharmacological interventions are not always effective in treating symptoms and sometimes can be greatly aided by complementary therapies such as prayer, relaxation exercises, music therapy, guided imagery, healing touch and breathing exercises (among other things) — all of which chaplains can provide.

It is also important to note that physical symptoms very often have spiritual dimensions. At times, what a patient may be feeling and reporting as a physical symptom may in fact be rooted in spiritual pain. Oftentimes, patients do not have a spiritual vocabulary for describing their pain or distress and may report distress primarily in bodily terms instead.

Another way in which hospice organizations may foster good integration of spiritual care is by offering spiritual care to all patients from the starting point of admission. In my organization, Hospice of the Bluegrass in Lexington, KY, chaplains are required to participate in an initial team visit with all patients (unless they refuse a chaplain) within five days of admission. This initial visit communicates to patients that their spiritual needs make up an important element of their care.

Chaplain Tim Ford has written on the importance of the spiritual dimension of healthcare:

Spirituality has long been a recognized part of medical care and is often named in the mission statements of various institutions. Early medicine was inseparable from religious care but with the rise of empirical medicine, the two modes of care became radically, some would say artificially, distinct. Today nurses, doctors and even supplemental services like occupational therapy are searching their collective professional souls to recapture their own spiritual values in clinical practice. Chaplaincy today
faces these questions not as an overt attack upon their clinical ‘turf,’ but rather an opportunity to expand their own historical conversations about these very same questions into an interdisciplinary dialogue.4

There is a tendency in healthcare to identify spiritual needs as secondary to physical issues. It is true that medical interventions are often needed in a timely manner in order to preserve or sustain life. However, instead of maintaining a system in which medical needs are treated first and spiritual needs second, it is possible to envision programs in which spiritual care may be delivered in conjunction with medical care, from the start. Not only would early spiritual interventions enhance medical care, but they may very well be needed ahead of (or at least at the same time as) medical care.

**We Are the Medicine**

Even when pain or other symptoms are strictly related to physical causes, and even if medications are effective in treating them, it still cannot be presumed that a patient’s physical distress has prevalence over his or her spiritual distress. Spiritual pain may be more pressing, especially at the end of life.

Some of the unique contributions we bring as chaplains include:

- Our ability to listen. Since we are trained in listening, we may be able to hear important health-related information which patients may not be able to tell nurses and doctors.
- An identity and calling as healers, practiced through healing rituals and other therapies such as prayer, meditation, and deep breathing.

Our work is rooted in relationships — where healing takes place. Dr. Sauders has said, “We are the medicine.”

Patients have the expectation that they can engage in reflection, contemplative practices and rituals with chaplains — and this is empowering to patients. Rather than being in a passive position of having medications and treatments administered to them, they are able to participate in their healing by the sharing of themselves. In my opinion, this is where the real medicine occurs.

*This article was originally published by Healthcare Chaplaincy’s PlainViews (Vol.10 No.5).*

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Alice Tremaine is a board certified chaplain and an ordained Baptist minister. She currently serves as a chaplain for Hospice of the Bluegrass (based in Lexington, KY) and as the co-leader for the regional chaplaincy peer group of the Kentucky Association of Hospice and Palliative Care. She is also the creator and manager of http://prayersforhealth.com.

References
National Hospice and Palliative Care Organization’s  
2013 Virtual Conference - November 4th-8th, 2013

Loss, Grief and Bereavement
Helping Patients, Families and Communities

Join NHPCO and hospice and palliative care professionals committed to holistic care of those at the end of life for a national virtual learning opportunity exclusively focused on the loss, grief and bereavement needs of patients, families and communities. The experiences and many ways loss permeates, impacts, influences and defines the end-of-life experience will comprise the innovative and cutting-edge content of this learning opportunity.

This online event will offer all the benefits of an in-person conference without the added time and expense of travel:

• Live-broadcast plenary sessions featuring national speakers
• Concurrent sessions
• Ignite sessions (Quick, succinct and “to the point” presentations)
• Networking opportunities
• Exhibit hall featuring national vendors

Mark the dates on your calendar and prepare to join colleagues from across the country in this unprecedented learning event!

Visit us at http://www.nhpco.org/education
Each year, NHPCO produces a collection of professionally designed display ads with a new theme and tagline. The goal is to make outreach easier and more affordable for all members, large and small, during National Hospice Palliative Care Month and beyond, but also to encourage a strong and unified message among providers nationwide.

This year’s tagline, “Hospice | Care on Your Terms,” serves to reinforce one of the very positive aspects of hospice care that was identified by focus group participants during Phase 1 of the NHPCO Affirming Hospice Campaign.

Shown above are the full-page versions of the three ads in this collection that feature the “2013 Hospice Palliative Care Month” banner. Evergreen versions (without the banner), along with half-page and poster-size versions are also available — and all are posted online at www.nhpco.org/outreach. Lots of options to meet every program’s needs and budget!

Additional new materials are also available this year. See page 24 to learn more about them.
Answers to Common Questions

Will there be a hospice quilt and quilt poster this year?
No, there will not be a hospice quilt or quilt poster. That was a special campaign that was launched in 2000 and concluded with the 2011 hospice quilt. However, NHPCO has created poster-size versions of the three display ads in this new collection that you can download and quick-print—even incorporating your organization logo if you so choose.

Do I need permission to personalize the ads, or to use the photos or copy in other materials?
No, NHPCO members (with current, paid membership) do not need permission to utilize these ads in any way that helps them promote their organization and services. In fact, NHPCO encourages members to use the materials as much and however they wish to advance the hospice palliative care message!

How do I personalize the ads and insert my organization logo?
The ads are provided as high-resolution PDFs that can be opened and easily manipulated in Adobe Acrobat Professional (7.0 or higher) or Adobe Illustrator. For written instructions, see www.nhpco.org/outreach.

Where can I find the “Member of NHPCO” logo if I also want to insert that?
Various versions of the “Member of NHPCO” logo are available online (on the same page as the ad collection). Members can use the logo in these display ads, on other materials, or even on their website to visually communicate their commitment to quality.

Can I continue to use last year’s ads if I want?
Yes, members are welcome to continue to use the display ads in the 2012 outreach collection if they wish. In fact, the 2012 materials are still posted online for easy access.

Questions?
If you have any questions, contact the NHPCO Solutions Center at 800-646-6460 (8:30 a.m. to 5:30 p.m. ET).
Additional Resources Available Online

**New — LIVE Without Pain Ads**
In May of 2012, NHPCO’s Caring Connections unveiled the LIVE Without Pain consumer campaign in partnership with Purdue Pharma, LP. The goal is to empower patients and family caregivers to advocate for expert pain relief in all care settings through education and how-to resources.

As part of this initiative, NHPCO has developed a full-page display ad to help providers promote their expertise in pain management. Shown below are the two versions of this ad — the one with the banner can be used during September “Pain Awareness Month” while the other can be used throughout the year.

You can also use the white space in the lower left corner of the ads to feature your organization logo and/or contact information.

**New — Visuals to Use in Social Media**
A selection of visuals, using this year’s new theme and tagline, have also been created for use on Facebook, Twitter, and your website.

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**Facebook Banner**

**Twitter Banner**

**Website Banner**

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**PAIN AWARENESS MONTH • SEPTEMBER 2013**

**DON'T SUFFER IN SILENCE.**

When you are in pain, it’s hard to focus on anything else. Physical pain can take away peace of mind, comfort, enjoyment and most of all hope. Learning what you can do to manage your pain can help you focus on other parts of your life and enjoy your days.

Learn more about dealing with pain at caringinfo.org/pain

Withou

ut Pain

_learn more about dealing with pain at caringinfo.org/pain

24 NewsLine
Visit the NHPCO Website to Access These Materials

**Plus:**

**Basic Outreach Guidance**
- An Introduction to Outreach
- Event Planning Guide
- Media Relations Tips

**Media Outreach Tools**
- Press Release for National H/PC Month
- Letter to the Editor (National H/PC Month)
- Letter to the Editor (from a family member who is now a volunteer)
- PSA Radio Scripts
- National H/PC Month Proclamation

**Evergreen Article Collection**
- Hospice and Palliative Care: Making a Difference
- Don’t Wait to Talk About the Care You Would Want
- Facts About Hospice Care Everyone Should Know
- How Can Palliative Care Help?
- Paying for End-of-Life Care
- Plus More

**Background Documents**
- NHPCO Facts & Figures on Hospice Care in U.S.
- NHPCO Facts & Figures: Pediatric Palliative and Hospice Care in U.S.
- Common Misconceptions About Hospice

PowerPoint presentations and a range of outreach guides for various underserved populations are also available.

Visit www.nhpco.org/outreach.
Former CMS administrator, Don Berwick, MD, announced on June 17 that he is running for governor of Massachusetts. “As a doctor, an educator, an innovator and someone who has dedicated his professional career to making things work better and to helping people — I am ready to lead,” Berwick noted in a statement formally announcing his candidacy.

That dedication to ‘making things work better’ came through loud and clear when Berwick delivered the opening plenary at NHPCO’s 28th Management and Leadership Conference in April: “Rapidly Improving Care in the Last Years of Life to Achieve the Triple Aim.”

Due to its popularity, NHPCO made the plenary available as a Webcast — but only for a limited time.

If you haven’t yet watched it, please do so before it expires on August 14. Members pay a nominal fee of $105, with CE/CME available for counselors, nurses, physicians, and social workers.

To learn more, visit the NHPCO website.

There are now 20-plus Webcasts available to members through NHPCO’s End-of-Life Online, and many offer CE/CME. Visit the Webcast landing page to view the list. Then click on any Webcast to learn more about it and purchase access.
On May 6, 2013, the HHS Office of Inspector General issued a memorandum report on the use of general inpatient care (GIP) among hospices in 2011.

For those members who may have missed the NHPCO summary of this report (issued as Regulatory News on May 7), the report discusses the use of GIP, length of stay, and location of GIP (i.e., hospice inpatient unit, hospital or skilled nursing facility).

Also included in the report is an analysis of hospices which have their own inpatient facilities, compared to those which use hospitals and skilled nursing facilities.

A second section of the report analyzes the group of hospices which did not provide any GIP to patients in 2011 and calls for additional analysis by CMS on why that level of care was not provided for any patient.

To Learn More

The NHPCO summary includes a snapshot of key data from the report, including data on the use of GIP, the sizes of hospices studied, and where GIP was provided. It also summarizes OIG’s next steps and its suggestions for further action by CMS.

- Read the NHPCO Summary
- Read the Complete OIG Report
Mary Patchett Receives Hospice Nursing Award

Longtime hospice nurse, Mary Patchett, RN, was named the recipient of the 2013 Kathleen Schroot Memorial Award by Hospice of the North Shore & Greater Boston during National Nurses Week in May.

Patchett, a nurse with the organization for the last 19 years, exemplified the traits that Schroot was so well known for, including compassion and an acceptance of others. Schroot was the first registered nurse hired by the organization in 1989, and passed away in 2010 after a long illness.

John Saroyan Appointed Medical Director of BAYADA Hospice

BAYADA Hospice has appointed John M. Saroyan, MD, FAAP, as the full-time medical director for its operations in Vermont and New Hampshire.

For the past 10 years, Dr. Saroyan has been a faculty member in pain management and palliative care at Columbia University, most recently as associate clinical professor. He was also program director for the Hospice and Palliative Medicine Fellowship, and is board certified in pediatrics, with subspecialty certification in hospice and palliative medicine.

Med Students Simulate Patient Encounters to Enhance Understanding of EOL Care

At the Texas A&M Health Science Center/College of Medicine, students have developed palliative care scenarios which they “act out” at the institution’s Clinical Learning Resource Center. The goal is to enhance their understanding of hospice palliative care, and improve their skills in the delivery of difficult news and what comes next when there is no curative path forward.

These simulated encounters are observed live via a video feed and students are given immediate feedback on their communication skills. They can also review the recorded encounter later to critique their own performance.
Regional Hospice and Home Care Breaks Ground on Facility With Private Patient Suites

On June 25, Regional Hospice and Home Care of Western Connecticut (based in Danbury) broke ground on a 30,000-plus, square foot hospice facility that will include 12 private patient suites and many amenities, such as a spa with massage therapy; Reiki and hair salon; and a meditation garden. The facility is scheduled to open in November 2014.

Father Louis Richard Receives National Recognition

Father Louis Richard has received the 2013 Jefferson Award for Public Service for his efforts to help found Hospice of Acadiana (based in Lafayette, LA).

The Jefferson Awards are a prestigious national recognition system honoring community and public service in America, and are presented on the both the national and local levels.

While pursuing graduate work in Belgium, Father Richard attended a symposium on “Death and Dying” by Dame Cicely Saunders and later worked at St. Christopher’s Hospice. On his return to the states, he worked with other members of the Lafayette community to found Hospice of Acadiana in 1983. A Roman Catholic priest, Father Richard is currently pastor of Sacred Heart of Jesus Church in Broussard, LA.

National Center Extends Special Thanks to Summer Interns!

This summer, NHPCO and its affiliates were pleased to offer eight deserving students summer employment at the National Center for Care at the End of Life — great exposure for them and a great help to staff.

Front Row: Ayelia Ali, Austin College. Back Row (l to r): Douglas Franchitto, American University; Josie Mace, American University; Evan Sullivan, Carrboro High School (Carrboro, NC); Nora Azzawi, Mount San Antonio College; and Hayden Peters, University of Arkansas. Not shown: Sheridan Leong, College of William and Mary; and Bryce Leong, George Mason University.
The implementation date for the HIPAA Omnibus Rule is September 23, 2013! This means all providers must update their HIPAA Notice of Patient Privacy (NPP) and ensure that all current patients receive the revised notice and explanation by September 23.

The revised NPP must contain the following:

- Standard heading.
- Who must abide by the NPP.
- How your organization uses and discloses Private Health Information (PHI) for treatment, payment and operations (with examples).
- For covered entities engaging in fundraising, a statement that an individual can opt out of fundraising communications.
- For providers, a statement that the covered entity must agree to restrict disclosure to a health plan if the individual pays out of pocket in full for healthcare service.

The NPP must also contain the following:

- Statement regarding the individual’s right to receive breach notifications (how they are informed of a PHI breach must be included).
- Statement regarding the sale of PHI for marketing or other purposes that require authorization.
- Statement that the covered entity reserves the right to change the terms of its NPP and to make the new NPP provisions effective for all PHI it maintains.
- Statement that the covered entity will provide individuals with a revised NPP in accordance with the rule.
- Brief description of how an individual may file a complaint with a covered entity.
- Statement that the individual will not be retaliated against for filing a complaint.
- Statement containing the name or title, and telephone number of a person or office to contact for further information as well as the date the NPP, as revised, became effective.

Healthcare providers must post their revised NPP on their website (if applicable), and must display the NPP in a prominent location on their premises. Patients who are receiving services for the first time after modification of the NPP should be provided with a copy of the revised NPP. Consistent with the existing rules, providers should retain copies of previous versions of their NPPs as well as any written acknowledgements of their patients’ receipt of NPPs.
Preconference Seminars:  
September 24-25, 2013

Main Conference:  
September 26-28, 2013

Sheraton and Westin at Crown Center  
Kansas City, Missouri

14th Clinical Team Conference and Pediatric Intensive

In Cooperation with, the Missouri Hospice and Palliative Care Association

www.nhpco.org/ctc2013
The Office of Inspector General (OIG) has created a tutorial on how to use its LEIE downloadable exclusions database, with helpful tips for searching and verifying individuals and entities. Watch the tutorial now.

As a reminder, it’s important that Medicare-funded programs not hire individuals or entities on the LEIE (List of Excluded Individuals and Entities) since doing so puts the program at risk for a civil monetary penalty. For background on the LEIE, visit the OIG website.
Palliative Care in Tanzania Now Integrated into National Health Care System

National Level Policy Change Heralded by Providers and Advocates

In May 2013, a dream was realized for palliative care providers, advocates, and beneficiaries of palliative care in Tanzania, when the Ministry of Health and Social Welfare ratified its long-awaited Palliative Care Policy. This statute unifies the work of Tanzanian palliative care providers, and further integrates palliative care into the national health care system.

The ratification of the Palliative Care Policy was celebrated by Tanzanian palliative care stakeholders throughout the world. Dr. Elias Muganyizi, executive director of the Tanzania Palliative Care Association, described the development as a dream come true. Marleen Masclee, programmes manager at APCA, said, “Thousands of people across Tanzania will no longer have to live in unnecessary pain and this is a tribute to everyone involved.”

The significance of a policy change such as this is shown in Rwanda, which was one of the first countries in Africa to implement a national palliative care policy, strategic plan and practice standards. Released by the Ministry of Health in 2011, these policies commit the country to provide high-quality yet affordable palliative care services to all Rwandans suffering from life limiting illnesses by 2020.

As a result, palliative care services have been scaled up throughout the country including at district hospitals and community-based palliative care providers. According to Dr. Christian Ntizimira, a Rwandan physician and palliative care pioneer, “Previously palliative care was only available to those with sufficient resources to seek such services abroad. Now, patients with end-stage diseases in Rwanda have access to palliative care at their doorstep.”

As the work of African palliative care development continues, policies that promote the integration of palliative care into the broader health care system will be critical. FHSSA congratulates all those who worked tirelessly where integration has occurred and continue to support those who strive to make palliative care integration a reality.
A New Opportunity for Partners to Raise Funds and for Individuals and Organizations to Support Palliative Care

This September, at NHPCO’s Clinical Team Conference, FHSSA will launch the “FHSSA Champions Campaign.” FHSSA Champions are a level of FHSSA supporters who work to raise funds to support a specific project or goal of an African organization in need. Champions differ from FHSSA Partners in that their commitment is for a one-time purchase or project.

Over the course of the campaign, which is scheduled to close at the 2014 Management Leadership Conference, FHSSA will work to recruit 10 individuals/groups/organizations to become FHSSA Champions. FHSSA Champions can range from a hospice that wants to be involved in end-of-life care in Africa without making a long term commitment, to a school or business seeking to support compassionate care in Africa, to an inspired individual wanting to make a difference globally. This is FHSSA’s way of opening up the opportunity for people not necessarily associated with palliative care to show their support for our work.

Currently, FHSSA is working with our American partners to create a list of tangible needs for their individual African partners. Some examples may include the purchase of medical supplies to be bought in-country, bicycles or a car for transportation of team members, sponsorship for training courses or conferences for hospice staff, or other items that may be needed to strengthen the African program.

If you are a U.S. FHSSA partner that wishes to submit a list of tangible needs for your African counterpart, or a person/organization interested in becoming a FHSSA Champion, please email FHSSA Program Coordinator, Jeremy Taglieri, at jtaglieri@fhssa.org for more details.

A New Partnership Program Survey for 2013

FHSSA’s annual partnership survey, which is completed annually by both African and U.S. partners as part of their partnership agreement, is a critical tool in helping us better understand the challenges facing our partners, how these circumstances affect the quality of the partnerships, and how FHSSA can improve its services.

Currently, FHSSA and NHPCO staff members are reviewing the survey, discussing how it can be both sharpened and shortened. Our goal is that the 2013 Yearly Report will be a more effective tool that will provide us better results with a higher rate of participation.
Longtime Hospice and Palliative Care Advocate, Dr. Zipporah Ali Receives Honorary Doctorate

FHSSA congratulates Dr. Zipporah Ali, executive director of Kenya Hospices and Palliative Care Association (KEHPCA), on receiving an honorary doctorate from Oxford Brookes University. Dr. Ali, known as “Zippy” by colleagues and friends, has devoted her career to developing and expanding palliative care in Africa. She was one of six leading figures from the worlds of medicine, motorsport, healthcare and business, and the only African to receive the award.

Zippy’s own experience of watching her brother suffer and die from cancer at the age of 33 led her to become one of the first students to complete a medical school course run in partnership with the first hospice in Nairobi. As a young doctor, she felt ill-equipped to care for patients with life-limiting illnesses since palliative care had not been a part of medical school curriculum at that time.

Dr. Ali shared this message as she accepted the award, “It has been an honor and a humbling experience to work towards changing the way patients and their families are treated at a most critical time, when cure is no longer possible; at a time when they need our support most, a time when most doctors will say ‘there is nothing more we can do for you.’”

She added, “What this award symbolizes is the growth and evolution of hospice and palliative care in Kenya as well as many other countries across the world.”

FHSSA has worked closely with Zippy for many years in her role as the leader of KEHPCA, a FHSSA Partner, partnered with Hospice and Community Care in Lancaster, Pennsylvania. Under her leadership, KEHPCA was awarded the prestigious Red Ribbon Award at the XIX International AIDS Conference in 2012 for work conducted within the community to improve the quality of life for those living with cancer and HIV/AIDS.
Meet Jeremy Taglieri, FHSSA Coordinator

Where are you from?
I think of myself as a “hometown” kind of guy. I was born, raised, and went to college in upstate New York near Albany. I come from a very tightknit community, in fact, to this day, some of my closest friends are ones I met back in the first grade.

What was the focus of your education?
I have a deep interest in social issues. As such, I received my bachelor’s degree in Political Science from Union College in Schenectady, NY. While in college I had thought that I would work for a political think tank after graduation, but I eventually realized that I wanted to take a more hands-on role in solving problems. As a result, I became very active in community service.

What was the first step in your career following college?
Directly after college, I wanted to continue working in community development. So I became an Americorps volunteer in my college town where I led an effort to renovate an inner-city park.

After Americorps, I joined the Peace Corps and was sent to work in the Republic of Moldova which is a small, former soviet country located between the Ukraine and Romania. As a Peace Corps Volunteer, my primary assignment was to assist in the development of a small, home based care hospice in the rural south of the country. The two years I spent there were extremely formative.

In Moldova, hospice care is still a new concept. The hospice director, Maria, had worked for many years as a nurse in the district hospital where she saw the need for palliative care in her community. She decided to quit her job, open a hospice, and dedicate her life to aiding those facing life-limiting illness. People thought she was crazy, but she was that kind of person. Working with her was a real honor.

Through my experience at the hospice I learned a lot about the need for and challenges facing palliative care in the developing world. Though my role was primarily administrative, I occasionally joined the medical team on home visits. I have so many memories seeing the impact our hospice had on people’s lives. I remember one day a husband of a patient who had recently passed away called our office and read us a poem he had written about his wife. It was so powerful.

What interests you most about working for FHSSA?
When I arrived home from the Peace Corps, I had a strong desire to continue working in international palliative care development. I was fortunate that there was a position open with FHSSA. I think the most interesting part of my work is seeing the process of palliative care development from a very different perspective. It is interesting comparing and contrasting programs in Africa and Eastern Europe, while there are differences, there is a striking amount of similarities.

In the short time I’ve been with FHSSA I’ve had the pleasure of working with and meeting many of our wonderful partners, both American and African. I look forward to meeting many more of them in the future!