National Hospice and Palliative Care Organization

March 2007
Quarterly Insights Edition

NewsLine

25 years of the Medicare Hospice Benefit

Faces behind the legacy
Perspectives on the future
Your Membership

Dues at Work:

- **Family Evaluation of Bereavement Services**, a new survey tool enabling hospices to evaluate their services (nhpco.org/febs).
- **Expanding Access to Hospice Care for People with ALS**, a new monograph published by NHPCO to help clinicians identify when someone with ALS may benefit from a referral to hospice, available from the Marketplace (nhpco.org市场place; item #821011).
- NHPCO quality measures and data have been incorporated in reports on U.S. healthcare quality and disparity released by the Department of Health and Human Services.
- The Public Policy division hosted a day-long summit looking at issues relating to the Medicare reimbursement CAP.
- A comprehensive member survey was sent out collecting feedback about how we’re serving you, our members.
- NHPCO members were offered up to 100 free copies of a 60-page new consumer resource on end-of-life financial issues.

Stay on top of all the activity at NHPCO through the weekly e-communication, NewsBriefs or check the “Breaking News” section of nhpco.org.
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In this first quarterly edition of the year, NHPCO extends special thanks to these exemplary members for service to their disciplines and to the end-of-life field.

**CHAIR**
Bob Miller, BA, MDiv
VITAS Innovative Hospice Care® • Miami, FL
Bob Miller joined VITAS in 1989 and is currently senior vice president of clinical development and bioethics. Prior to becoming chair of NCHPP, Bob served a three-year term as the Research/Academics/Education Section Leader.

**ALLIED THERAPIST**
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Richard Briggs has 20 years of experience as a physical therapist with Enloe Homecare and Hospice. He also writes, lectures, and consults with agencies to integrate physical therapy into hospice care through his practice, Hospice Physical Therapy Associates.

**BEREAVEMENT PROFESSIONAL**
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Patti Homan is program director for the PATHways Center for Grief & Loss at Hospice of Lancaster County. For more than 20 years, she has focused her clinical training study and practice in the areas of death and dying, crisis, trauma, and loss. In addition to her role as Section Leader, Patti is a fellow in thanatology with the Association of Death Education and Counseling where she serves as chair for its Body of Knowledge committee.

**CEO/EXECUTIVE DIRECTOR/PRESIDENT**
Dale O. Knee
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Dale Knee’s distinguished career in the end-of-life care field spans 35 years. Under his leadership as president/CEO of Covenant Hospice, the program has become one of the largest non-profit hospice systems in the nation, serving 35 counties in Florida and Alabama. In addition, Dale is active at the local, state, and national levels, including service on the Federal Workgroup on Veterans and Hospice Affairs.

**CNA**
Cassandra Cotton, CHPNA
Nathan Adelson Hospice • Las Vegas, NV
Cassandra Cotton joined Nathan Adelson Hospice more than 15 years ago as a nursing assistant and currently serves as its community relations and outreach coordinator. In addition to her work as Section Leader, Cassandra has devoted her time and expertise to educating the African-American community about hospice care. She is founder of the Nevada Black End-of-Life Care Coalition, chair of the Caring Touch Ministry, and a member of the National Advisory Committee for Caring Connections.

**DEVELOPMENT/PUBLIC RELATIONS/MARKETING**
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Anne Hochsprung is vice president of finance for The Hospice of the Florida Suncoast, where she has worked since 1999. Prior to joining the hospice, she spent 20 years working in the healthcare industry. In addition to her role as Section Leader, Anne is part of the faculty for NHPCO’s Management Development Program.

**NURSE**
Pat Gibbons, BSN, CHPN
Beacon Place • Greensboro, NC
Pat Gibbons is director of Beacon Place, the 14-bed hospice facility operated by Hospice and Palliative Care of Greensboro. Under Pat’s leadership, the facility has been a nursing student placement site for RN to BSN students and baccalaureate nursing students. In addition to her work as Section Leader, Pat is a faculty coach in NHPCO’s Clinical Excellence Collaborative.

**PERFORMANCE IMPROVEMENT/QUALITY ASSURANCE**
Vice-Chair
Shareefah Sabur, MNO
Hospice of the Western Reserve, Inc. • Cleveland, OH
Shareefah Sabur has been at Hospice of the Western Reserve since 1993 and serves as director of planning and evaluation. In addition to her role as Section Leader, she serves on NHPCO’s Standards Committee and is co-chair of NHPCO’s Quality Advisory Council.

**PHARMACIST**
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Phyllis Grauer has been a palliative care consultant pharmacist for over 20 years and is founder of the Palliative Care Consulting Group. Following PCCG’s recent merger with Hospiscript
Services, Phyllis has assumed the role of vice president of clinical development. In addition to serving as NCHPP’s Pharmacist Section Leader, she is an assistant clinical professor at The Ohio State University College of Pharmacy.

PHYSICIAN
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Joan Harrold is medical director and vice president of medical services for Hospice of Lancaster County. In addition to serving as NCHPP’s Physician Section Leader, she is president of the Pennsylvania Hospice Network board of directors, a trustee of the American Board of Hospice and Palliative Medicine, and faculty member for the NHPCO Physician Leadership Development Program.

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SOCIAL WORKER
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Sherri Weisenfluh has over 25 years of experience as a licensed clinical social worker. She currently serves as associate vice president of counseling for Hospice of the Bluegrass, a position she has held for 15 years. In addition to her service as Section Leader, she teaches part-time at the University of Kentucky.

SPIRITUAL CAREGIVER
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Kathy Roble has been director of volunteer services for The Hospice of the Florida Suncoast since 1994 and has been a frequent presenter at local, state and national conferences on topics related to volunteer management. In addition to her role as Section Leader, she serves on the education committee of Florida Hospices & Palliative Care, Inc.
25 Years of the Medicare Hospice Benefit
Since the Medicare Hospice Benefit was enacted in 1982, it has come to represent so much to so many different people. To the hospice pioneers, advocates, and volunteers who helped make it happen. To the field’s working professionals who saw the Benefit as a means to do more for more people. And, perhaps most importantly, to the Americans who were able to live a better death because of it.

In this commemorative issue, we strive to portray the significance of the Benefit from each of these important perspectives. You’ll find a fascinating historical overview, punctuated by personal recollections from pioneers and advocates as they look back on this “political miracle” and discuss why it has withstood the test of time. And, you’ll hear from interdisciplinary team members from around the country on what the Benefit has meant for their disciplines and where their attention must be directed as hospice care continues to evolve.

In the concluding pages, Don Schumacher and John Kenagy focus on our future. As NHPCO’s president/CEO — and a hospice CEO for 20 years — Don speaks to those key concepts and principles he feels will help us build on our past success as we move forward, while John Kenagy offers keen insights as a leading surgeon, healthcare professional and scholar turned patient.

“What’s past is prologue to our future” are the words that greet visitors to the National Archives Building, not too far from the Capitol, where this picture was taken. Don references these words in his article, and why they hold special significance to him. Words that undoubtedly hold significance to each of us as well at this important juncture.
For Jay Mahoney, president of the National Hospice Organization from 1984 to 1998, and before that director of a hospice program in Boulder, CO, one of the most pivotal moments in hospice’s history — and in the establishment of the Medicare Hospice Benefit as a defining structure for end-of-life care in America — occurred on July 22, 1982. It happened during a debate in the U.S. Senate chambers over technical provisions of the Tax Equity and Fiscal Responsibility Act (TEFRA) related to the Internal Revenue Code.

That afternoon, Senator John Heinz (D-PA), with a clipboard in his hand, moved around the Senate chamber gathering signatures in support of an amendment to establish a hospice benefit and reimbursement under Medicare. He needed commitments from two-thirds of his colleagues to overcome an anticipated objection to his amendment on grounds that it wasn’t germane to the tax debate. Senator Heinz didn’t stop until he had the names of 68 senators on his clipboard and he could rise to request immediate consideration of his amendment.

Legislation to create a Medicare Hospice Benefit had been introduced the previous December in the House (H.R. 5180, sponsored by Reps. Leon Panetta, D-CA, and Bill Gradison, R-OH) and in the Senate (S. 1958, by Sen. Bob Dole, D-KS). Their bill enjoyed favorable hearings in the House Ways and Means Health Subcommittee in March of 1982, but budget issues blocked its way forward. When the House opted not to pass a version of the omnibus budget bill that year, there was no legislative “vehicle” to which the hospice proposal could be attached.

Mahoney described the events of that July day in a 1998 article in the Journal of Palliative Medicine and expanded on them for this NewsLine interview. “Why did Senator Heinz decide to do that — to pick up his clipboard and move around the Senate chamber gathering signatures? He was really sticking his neck out.”

Donald Gaetz, today remembered as a principal architect of the Medicare Hospice Benefit, was in the Capitol that day with Rev. Hugh Westbrook, his colleague from Hospice, Inc. (today called VITAS Innovative Hospice Care), based in Miami, Florida. “We had made a strategic decision to go straight to the Senate floor,” Gaetz recalls. “We were well-advised by Sheila Burke, Senator Dole’s chief of staff, and others in Congress who were helping us, essentially to take a single roll of the dice and attach our proposal to TEFRA,” he says.
“Hugh and I were pulling members off the Senate floor to the reception area — asking them to sign the amendment, one by one.” Most of the members had already been contacted multiple times by Gaetz, Westbrook and other hospice advocates in the National Hospice Education Project (NHEP), a lobbying organization they created with the sole purpose of getting a hospice benefit passed through Congress and implemented.

It was close to midnight in the packed chamber when Senator Heinz rose to propose the amendment, Gaetz says. He and Westbrook were sitting in the Senate Gallery, courtesy of Barbara Bush, another early supporter of hospice. “It was just one of those extraordinary moments. After Senator Heinz introduced his amendment, one by one other key sponsors stood up to extol hospice,” Gaetz recalls.

Their names, as captured in the Congressional Record for July 22, 1982, include some of the more prominent figures of recent political history from both sides of the aisle: John Glenn of Ohio, Robert Packwood of Oregon, Lloyd Bentsen of Texas, William Cohen of Maine, Dan Quayle of Indiana, Steven Symms of Idaho, Lawton Chiles of Florida, Chuck Grassley of Iowa, Bill Bradley of New Jersey, and Mark Andrews of North Dakota. “Afterward, we went out for pizza with Senator Heinz,” Gaetz recalls.

After that dramatic maneuver, the adopted hospice amendment enjoyed smooth sailing through Conference Committee and was signed into law by President Reagan on September 3. Final implementing regulations were published in the Federal Register on December 16, 1983, with a retroactive effective date of November 1. Then a small but steadily growing band of hospice providers started lining up for their certification surveys to qualify for Medicare reimbursement.

Today, few would question that the Medicare Hospice Benefit has been the principal organizational and financial driver for the extraordinary growth of hospice care in America. Hospice is a multi-billion dollar industry, traded on the New York Stock Exchange, while over 4,000 hospice providers care for more than 1.2 million terminally ill Americans each year, the majority of them covered under the Medicare Hospice Benefit. However, reaching that level of success has not been easy or without its conflicts — within NHO and the hospice community, with other provider types, or with the government.

This article attempts to shed some light on the history and legacy of the hospice benefit on its 25th anniversary — why it was designed the way it was, how it reflected the values of key advocates, how it has managed to survive without major alterations to its fundamental principles, and how a small band of determined advocates was able to achieve so much for dying patients.
History of Hospice
The history of hospice care in America has been told many times. A short version begins in 1963 with the first of a series of lecture tours by Dame Cicely Saunders, then in the process of organizing St. Christopher’s Hospice as the prototype for the modern hospice, wedding a centuries’ old tradition of spiritually inspired service with up-to-date scientific techniques of pain and symptom management and grief support. St. Christopher’s, located in Sydenham, a suburb of London, England, opened in 1967 and has since been the model and teacher for hospices around the world. The first U.S. hospice opened in New Haven, Connecticut in 1974, established by a determined group led by Florence Wald, Dean of Nursing at Yale University, who had been inspired by Dame Saunders’ visit to New Haven.

Dennis Rezendes, the first executive of Connecticut Hospice, told NHO in 1989 that he had recognized the need for a hospice benefit and reliable funding stream at the time of the First National Symposium on Hospice Care, held in Connecticut in 1975. “It was clear that we would not survive, unless we were tied into the healthcare reimbursement system,” he explained. At the same time, Rezendes was trying to form the National Hospice Organization in response to skyrocketing national interest in this new care model. He developed the proposal for this new organization with Zachary Morfogen and others at the second national hospice symposium in Boonton, New Jersey in February 1977. NHO was incorporated in April of 1978.

In October of that same year, at the hugely successful first NHO annual conference in Washington, DC, Joseph Califano, Secretary of the Department of Health, Education and Welfare, announced that the government would fund and study hospice demonstration projects to learn about the organization and cost of this new model of care. Califano had been lobbied hard by another hospice booster, Connecticut Governor Ella T. Grasso, one evening after missing a flight back home from Connecticut.

From more than 200 applications, 26 programs were chosen as demonstration hospices (see page 13 for the list of programs). These programs received cost-based reimbursement — in other words, payment tied to the actual costs they incurred in caring for patients and then submitted to the government for reimbursement.

Other forces were contributing to ferment regarding hospice’s future. Early in its existence NHO appointed a task force to painstakingly write Standards of a Hospice Program of Care. Released in 1979, these standards have proven remarkably durable, although they described a model of care, not a payment structure. The Joint Commission on Accreditation of Hospitals had begun work on its hospice accreditation program in 1981. At the same time, numerous members of Congress and their aides were hearing from constituents about the miracles hospice care had wrought in the lives of dying patients and their families — or else had personal experiences of their own with hospice — and were eager to help.

The Warner-Lambert Foundation, which had been an early philanthropic supporter of hospice development, provided funds for a study of the potential cost benefit of hospice care, achieved by substituting palliation and quality of life for expensive and futile aggressive treatments and unnecessary hospitalizations. These findings were later confirmed and extended by the Congressional Budget Office, which gave the hospice concept its seal of approval as being, at worst, budget neutral for the Medicare program.

A Grassroots Effort
Don Gaetz, a hospital administrator in Wisconsin, moved to Florida in 1978 with a strong interest in the hospice concept based on personal experience. He met Hugh Westbrook, a Methodist minister in Miami who had spearheaded a local volunteer hospice initiative. Together, they successfully applied for one of the 26 federal hospice demonstration grants. Gaetz and Westbrook also helped to design and pass Florida state hospice licensure law. Along the way they met Rezendes and discovered a mutual interest in politics and a desire to see the nascent hospice concept placed on a stronger and more permanent footing.
“In November of 1979, the three of us sat down together and agreed that we would establish a legislative initiative, take it to the new NHO board of directors, and see if we could interest them in endorsing it and taking it on. We even volunteered to do the work. But the NHO board wasn’t interested at that time,” Gaetz recalled for NHO’s 1989 10-year history. They also realized that they couldn’t wait for analysis of the demonstration projects to be completed, since they were expecting to lose their primary source of funding in 1982.

NHO was understandably divided on the issue and still debating what hospice was. “Meanwhile, we felt we had to go beyond esoteric debate and create a durable definition of hospice and an organized system of reimbursement to support it,” Gaetz explains. They also went to talk with Representative Leon Panetta who, in 1980, had introduced a bill making hospice a benefit under Medicare Part B, inspired in part by his own parents’ terminal illnesses. “We suggested that his was not the right bill for hospice, and explained that we had something else in mind.”

The three hospice pioneers co-chaired the National Hospice Education Project and set about identifying at least one advocate in every Congressional district in America, so that they could mobilize personal contacts with members of Congress. They also approached the Washington, DC law firm, Hogan and Hartson, for legal assistance and got assigned to an eager new associate, Ann Morgan Vickery. Together they started conceptualizing and crafting the benefit.

“Hugh and Don and Dennis were very good at organizing the grassroots while we at Hogan and Hartson knew the technical aspects of getting a bill passed,” Vickery explains. The first challenge was to develop a set of specifications for the bill, based on what hospice advocates said was important and using the Florida hospice licensure law as a model. Then the specs list had to be turned into legislative language, with the help of Ed Grossman, legislative analyst for the House Ways and Means Committee, and other supporters in Congress.

The proposal they came up with encompassed many radical provisions that today are familiar elements of the hospice model. At the time, they were designed to preserve the integrity of the hospice philosophy and the insights of existing hospice programs while offering programmatic flexibility to providers and cost-containment safeguards to the government. Some of the most familiar elements of hospice care already contained in the draft hospice benefit legislation included:

- Eligibility based on a six-month terminal prognosis;
- Hospice care as an alternative to conventional medical care;
- A defined hospice interdisciplinary team, including the nurse, physician, social worker and counselor, within a separate hospice organization;
- An emphasis on care in the patient’s home to the extent possible;
- Treating the patient and family together as the unit of care; and
- Bereavement support for the family after the patient’s death.

Today, few would question that the MHB has been the principal organizational and financial driver for the extraordinary growth of hospice care in America.
Planning, spadework, and endless discussions about the bill and how to get it passed were done by a small group — perhaps two or three dozen committed individuals, most of them from demonstration hospices. They convened in Washington, DC about once a month during the year leading up to the bill’s passage. For a photograph of many of these advocates on the steps of the Capitol, see page 6.

One of the determined grassroots advocates was Mary Taverna, who in 1979 quit her hospital job to become a volunteer nurse at Hospice of Marin in San Rafael, California — the country’s second hospice program. Taverna, who chaired a national steering committee of demonstration hospices, recalls the days before the demonstration project and how difficult it was to provide patients with 24-hour availability of symptom management and concrete services such as medications and supplies. Because the hospice was solely dependent on volunteers to get the work done, it mostly operated as a supplement or add-on to existing healthcare providers, not a distinct service. By contrast, demonstration hospices like Hospice of Marin were given reimbursement at cost to cover a broad range of direct services as needed by dying patients. “Our job then was to provide the services and submit the data,” Taverna recalls. “Those of us in leadership positions in the hospice community wanted the demos to be successful. As the demos drew closer to their completion, we saw that HCFA wasn’t doing much to complete the data analysis,” Taverna says. In fact, the final report on the demonstration projects by researchers at Brown University wasn’t delivered until 1986, three years behind deadline. “If the demos stopped, many people enrolled by those hospices would lose that level of care. We felt we couldn’t let this happen. Hugh and Don understood that we should move beyond the demonstration process and go directly to Congress, and they knew we needed to act quickly.”

However, there was no consensus among members of the hospice movement about the advisability of this approach. “Smaller hospices absolutely objected to structure and accountability of any kind. This great division in our community was a big part of our challenge in advocating for the benefit,” Taverna says.

One of those who was not convinced about the structure of what became the Medicare Hospice Benefit was Howard Bell, founder of the Minnesota Coalition for Terminal Care in 1977, first coordinator of the hospital-based hospice program at Abbott-Northwestern Hospital in Minneapolis starting in 1981, and a member of the NHO board from 1982 to 1986. “It was more about tweaking the design,” he recalls today. For hospital-based hospices such as Bell’s, the 80/20 rule limiting inpatient care was particularly threatening, along with the requirement that core staff had to be employed by the certified hospice.

“The benefit was a miracle and visionary. Those of us in the minority, we cared about the same thing, which was preserving the values of hospice care. I would still maintain that our difference of opinion had a positive role in the ultimate outcome, by bringing important issues to the fore.” Still, Bell says, those times were difficult emotionally because things got highly politicized within the hospice movement, at the national meetings, and even on the NHO board.

Carolyn Cassin, who today directs Continuum Hospice Care in New York City, had founded a hospice in Battle Creek, Michigan in 1981 with a grant from the Kellogg Foundation. Part of fulfilling that grant was an analysis of the long-term sustainability of hospice, so she was naturally interested in the work of the NHEP initiative.

“I was there on behalf of community people like myself who wanted to find a way to make this wonderful thing called hospice work,” she says. “We were going to Washington every month. I remember all the meetings...”
we had at the offices of Hogan and Hartson. Those meetings were tense and high energy, with fervent debate bordering on anger because people were so passionate. We’d stay 10 hours and then a group of us would march up the hill to the Capitol. Some staffer would come in and say, ‘That will never get passed.’ So we’d go back and start over.”

Cassin says she believes nothing essential in the hospice concept was diminished by the necessary compromises of the political process and the agreements on how to control hospice expenditures and ensure budget neutrality. “It was clear to us that there had to be parameters to reimbursement. Congress would never accept an open-ended benefit. But there were fundamental premises on which we planted our stake, such as the idea of a separate provider category for hospice. Without that, we were afraid we’d lose control of hospice.”

**A Political Miracle — Then What?**

For Gaetz and other observers, it was the dedication and persistence of the hospice advocates and their supporters that carried the day in Congress. “Hospice people lobbied, pestered, begged and educated their members of Congress.” He has countless stories illustrating that dedication, such as Iris Kozil from Alive Hospice in Nashville “driving across Tennessee in a snowstorm to meet with a young Congressman named Al Gore in a truck stop. The reason he agreed to meet with her was only because she wouldn’t give up asking,” Gaetz relates.

“When the Medicare Hospice Benefit passed, not one hospice program in America was qualified to provide the benefit. Those of us who pushed for its enactment based it on what hospice care ought to be, instead of just describing what hospice was or designing it for provider convenience. Policy decisions were made on purpose — based on value judgments about care of the terminally ill patients and what those patients were telling us,” he says. By contrast, most of the benefit’s opponents, including the big healthcare lobbies, seemed to be arguing from economic self-interest.

Hospice was the only new health service entitlement created in the first Reagan administration. Leon Panetta described it as “nothing less than an organizational and political miracle.” However, once the Benefit was passed, there still were lots of details to work out. Implementing regulations had to be developed within the federal Health Care Financing Administration (HCFA), and the authorizing legislation was vague on a number of key points, including how the benefit should be paid. Some expected it to be fee-for-service, justified by cost reports, just like for hospitals, home health agencies and other providers.

A federal official assigned to help draft the regulations, Tom Hoyer, took such an interest in making the Benefit work that he remained the leading government expert on hospice policy until his retirement in 2003. Hoyer continues to consult with NHPCO and other groups on hospice-related policy issues.

**Health Care Financing Administration Hospice Demonstration Projects, 1980-1982**

1. San Diego County Hospice, San Diego, CA
2. San Pedro Peninsula Hospital, San Pedro, CA
3. Hospice of Marin, San Rafael, CA
4. Hospice of Santa Barbara, Santa Barbara, CA
5. Hospital Home Health Care Agency, Torrance, CA
6. Boulder County Hospice, Boulder, CO
7. The Connecticut Hospice, New Haven, CT
8. The Elisabeth Kubler-Ross Hospice, Clearwater, FL
9. Hospice of Miami, Miami, FL
10. University of Massachusetts Medical Center, Worcester, MA
11. Hospice of the Good Shepherd, Waban, MA
13. Lutheran Medical Center, St. Louis, MO
14. Overlook Hospital, Summit, NJ
15. Hospital Home Health Care-Hospice Care, Albuquerque, NM
16. Cabrini Hospice, New York, NY
17. Genesee Region Home Care Association, Rochester, NY
18. Providence Medical Center, Portland, OR
19. VNA Home Hospice Program, Dallas, TX
20. St. Benedict’s Hospital & Nursing Home, San Antonio, TX
21. VNA of Vermont, Burlington, VT
22. Hospice of Northern Virginia, Arlington, VA
23. Medical College of Virginia, Richmond, VA
24. Community Home Health Care, Seattle, WA
25. Bellin Hospice, Green Bay, WI
26. Rogers Memorial Hospital/Hospice, Oconomowoc, WI

continued on next page
“Some of the provisions in the statute tied the government’s hand and generated a lot of controversy,” Hoyer says. “But these were all features the hospice movement’s advocates pushed Congress to adopt as a means of grounding hospice as an alternative form of care.” The argument for hospice’s cost containment potential had been a masterful sales pitch, Hoyer notes, but it would not have come true if HCFA had opted for a fee-for-service system. Under the prospective payment approach, “hospices were put on a budget from day one and given responsibility for their own success. It required them to act more like a business. It made them more self-reliant.”

For the government, prospective payment was consistent with new directions in healthcare coverage, although it was probably a “hallway decision” that pushed hospice in this direction, Hoyer says. The decision to create four per-diem payment categories was also intended to give hospices more flexibility in how they applied services to individual patients. The actual rates, which were not in Hoyer’s purview, may have seemed to some in hospice like bad faith by the administration, but Hoyer prefers to see them as part of “a very intense price negotiation.”

NHO was open to the idea of prospective payment, which later would be applied to hospitals and home health agencies since it was both cost-effective and consistent with hospice’s care management philosophy. But it wanted 18 months of experience of cost-based reimbursement first to collect data for rate setting. Other healthcare groups, and the hospices they sponsored, had been surprised by the hospice bill’s passage, but now pressed for amendments that would permit the flexibility of other provider models. The National Association for Home Care got legislation introduced in 1983 for this purpose, but it did not advance.

Hospice advocates believed that the Reagan Administration was trying to kill the embryonic hospice benefit before it could get started. David Stockman, director of the Office of Management and Budget, told Congress that he did not believe hospice would be a cost-effective or even cost-neutral benefit. OMB projected that the Benefit would generate net expense of $350 million in its first three years of operation. Stockman proposed several remedies, including a limit on the total number of hospice enrollments nationally, which hospice advocates and their supporters in Congress would not accept. So they met with him several times to try to find a way around the impasse.

As the regulations ground through the government and rumors flew about the outcome, hospice advocates went back to make sure that Congress’ intent in enacting the benefit was honored. A memo to NHO members from Michael Rosen, chair of the Licensure and Reimbursement Committee, identified three problems: inadequate rates, misapplication of the 80/20 rule for inpatient days, and a faulty calculation of the overall cap amount.

The Benefit included an aggregate per-patient cap on Medicare hospice reimbursement. This cap, which was intended to preserve cost neutrality for the Benefit, reflected an amount equivalent to 40 percent of the costs of conventional care of Medicare beneficiaries with cancer in the last six months of life. But when the administration asserted that actual costs were lower than projected and therefore the aggregate hospice cap should be set at $4,200 per patient, NHO got a bill passed in 1983 restoring the cap to its previous level of $6,500 per patient. Then in 1984, NHO successfully lobbied for another provision raising the routine daily rate from $46.25, the figure in the final published regulations, to $53.17, which had been in the Benefit’s first draft rules published in August of 1983 and closer to the original projections of what it would cost to provide this level of care.

Controversy continued for several years, especially among rural and volunteer-intensive hospices and those that were part of home health agencies or practiced other coalition-type hospice care. Meanwhile, NHO, now the principal voice advocating in Congress and with HCFA for appropriate coverage for hospice care, built a strong record of legislative victories advancing the hospice concept. Many of these advances are outlined in the timeline on page 16.
Participation in the Benefit by hospices was disappointingly gradual. On June 15, 1984, there were just 91 certified hospices, while 12 others had withdrawn their applications, five had been denied, and 41 more were scheduled. In those early years, the very survival of hospice and of its unique Medicare payment structure sometimes seemed in doubt. By 1992, however, the Hospice News Service was able to declare that, based on the most recent NHO Hospice Census, the Medicare benefit was “here to stay”:

NHO identified 1,604 operational hospice programs in the United States in 1990, with operational defined as agencies actually providing comprehensive hospice services. At least 1,123 of these hospices are Medicare certified, while 140 more have certification pending. Thus, fully 70 percent of operational hospices are certified to provide the benefit today and nine percent are in the process of doing so. These numbers make it clear that the nine-year battle within the American hospice movement over the Medicare Hospice Benefit essentially is over. Some of them sooner than others, some more eagerly than others, but four out of five American hospices are or soon will be participating in the benefit.

**What Was the Legacy?**

Don Schumacher, NHPCO’s president/CEO, was on the board of a coalition-model hospice in suburban Boston when the Medicare Hospice Benefit was first proposed, and he was one of those who would have preferred allowing the coalition-model hospice to participate in Medicare. “What I came to recognize was that the development of the Benefit and of our industry was a labor of love — and unbelievably mission-driven. And we made such an impact,” Schumacher says.

“The birth of the hospice movement was a forceps delivery. It was tough work, but successful because of the incredible passion and compassion of its founders,” he adds. “Many of us in those days were naïve, but we had good guidance from strong leaders. Despite all of the struggles, millions of Americans have benefited. Hospice is one of the best things Medicare ever did. For me, the bottom line is that sometimes you have to take risks in order to achieve what you believe in.”

“The Medicare Hospice Benefit was a conscientious effort on the part of a group of people to stay true to the mission and philosophy of hospice care — and to build it into a benefit package,” Carolyn Cassin says. “To me it’s phenomenal that we were able to accomplish that. I still talk about it to every new volunteer and staff group here at Continuum Hospice. I say the Benefit is a formative document like the U.S. Constitution, and I am as enamored of it today as I was 25 years ago — even though there have been some interpretations of the Benefit that I don’t agree with. I think its legacy is a profound one — and I feel lucky to have been part of it. I felt — and still feel — that it’s so pure and close to the way we wanted it to come out.”

“I remember a lot of hard work but equally a lot of fun,” Mary Taverna recalls...
about those early days. “There was such urgency — everything had to be done in the moment. The phone would ring night or day — ‘Can you find someone in California who can speak with this Congressman? We need to find the right consumer.’” For Taverna, enacting the benefit felt like a now-or-never moment that determined the future of hospice care. “We had a winning message, so we were in the driver’s seat. But what if we had taken the wrong road? I think we took the right road, and the proof is in the pudding. The Benefit is still with us today.”

“Of course, there were people working in hospice care at the time the Benefit passed who thought the end had come — that reimbursement would kill hospice — or that institutionalizing it in law would somehow dilute the movement and its philanthropy and volunteerism,” Gaetz notes.

“Those who developed and passed the Medicare Hospice Benefit changed healthcare in America forever and for the better. Millions of families have received the benefits of hospice care because of the Medicare and Medicaid hospice benefits. Most of them would not have been cared for by hospice programs if the foundation had not been laid by the Medicare Hospice Benefit,” he concludes. “Instead of having a marginalized service delivered by a few well-meaning people in struggling organizations, the Benefit redirected resources from conventional care of the dying to hospice care, and now hospice is conventional care of the dying.”

References:
1. The National Hospice Organization, founded in 1978, changed its name to the National Hospice and Palliative Care Organization in 1999. NHO and other organizations are referred to by the name that was current at the time referred to.
4. Ibid.
Hospice is one of the best things Medicare ever did. For me, the bottom line is that sometimes you have to take risks in order to achieve what you believe in.

— Don Schumacher
Some of the Faces Behind the Legacy:

The Medicare Hospice Benefit was the result of many minds and hearts working toward a common goal. As one hospice leader remarked, it was hard work, but was successful because of the incredible passion and compassion of those involved. Together, these photos strive to capture that hard work, and the passion and compassion that not only made the Benefit happen, but have been the driving force behind hospice care’s success.

Our special thanks to the following organizations for sharing these photos from their archives:

Alliance Health Services
Mesilla Valley Hospice
Montgomery Hospice
Nathan Adelson Hospice
NHPCO
Northern Illinois Hospice
and Grief Center
and
The Hospice of the Florida Suncoast
A colleague recently retired, having been in hospice work since 1979. This caused me to stop and think about the fact that there was a time in hospice “before the Benefit.” There are a few of us around who do remember those times. We were a rebellious group who felt that there was a better way to care for the dying and that way was hospice. In those days, we all wore different hats.

As nurses, we used to joke on Friday afternoons about how many times that week we wore the hat of the social worker, the chaplain, and the volunteer. Back then, we also filled the role of the development professional because we needed to get enough money in donations and grants to keep our programs afloat. There were times when we did not know if we could. I remember having conversations with families about a sliding fee scale for our services. Then I remember hearing about this new government program called the Medicare Hospice Benefit. ‘No way’ did we want the government interfering in our work or telling us what we could and could not do. This could not be good for the movement!

However, we did need to find a reimbursement source to continue this valuable work and the Medicare Hospice Benefit could be that needed revenue stream. In my mind, I was able to make the transition — that this Benefit would give credibility, and therefore viability, to hospice. Only then did the Benefit become a good thing! Over the years, the Benefit has been a good thing. We have seen a steady growth in hospice and it is now much more than a movement.

While the Benefit has allowed hospice to grow and be sustained, there have been times when I felt that it has stymied our creativity of those early days. For example, I have heard phrases like “the Benefit does not pay for that.” We all know that the Benefit never stated what items, procedures, and drugs it would and would not pay for, just that whatever was needed had to be related to the terminal diagnosis.

Over time, we have learned how to utilize the Benefit to the advantage of our patients, families and programs. The AIDS epidemic challenged us all to look at how best to meet patient needs within the hospice concept. It helped to forge other challenges in the area of non-cancer diagnosis. Our patients are no longer coming to us with as predictable a disease course as those with cancer. We are able and willing to serve many more patients at the end of life. Even now, there are many more options available in cancer treatment that is many times considered palliative; another term added to our care continuum. Again, I have heard “but the Benefit does not pay for that.” The language of open access will again challenge our creativity to provide excellent end-of-life care to those needing and wanting the resource of hospice.

The Benefit is only a reimbursement mechanism for our programs. It is the Medicare Conditions of Participation and our own Hospice Standards that should dictate our care and practices. We must never allow ourselves to be held hostage to a revenue stream. We must always think outside the box and be ready and able to serve all who want this care at the end of their life.

Pat Gibbons is NCHPP’s Nurse Section Leader and serves as director of Beacon Place, a 14-bed hospice facility operated by Hospice and Palliative Care in Greensboro, North Carolina. Her first job with a hospice dates back to the early 80s, when she worked as an on-call RN with Good Samaritan Hospice in Brighton, Massachusetts. One of her proudest accomplishments was her involvement in the development of the first hospice inpatient AIDS program in Massachusetts — the Hospice at Mission Hill.
This 25th year of the Medicare Hospice Benefit is an opportunity for social workers to pause and appreciate how the legislation impacted the care of the terminally ill and their families. Two long-term employees of Hospice of the Bluegrass in Lexington, Kentucky — CEO, Gretchen Brown, MSW, and vice president of administration, Susan Swinford, MSW — share their comments on how the Benefit impacted patient care in Kentucky.

Gretchen Brown
I started with hospice in 1982; we had a group of volunteers, a half-time bookkeeper and a half-time volunteer coordinator. I took referrals, did all the administrative work, wrote grants, and anything else that needed to be done. Patients were given emotional support, but symptom management was somewhat unsophisticated. Nurses made visits and volunteers provided spiritual and psychosocial care. We also relied on volunteers to provide bereavement services.

As a social worker, I could see that patients and their families had great needs. Our patients were often younger than now and they had a strong desire to be at home. The program’s funding came from memorials and grants. It was hard to develop a budget because you didn’t know from day to day how much money would be available.

The Hospice Benefit was one of the best patient benefits developed by Medicare. In the beginning it was complicated. We started utilizing the Benefit in November of 1982, but did not receive funds till April of the next year. This caused some fear in the beginning and some programs resisted becoming Medicare certified.

I hired the first social worker when funding became stable. I love the social work role within hospice. Social workers have the chance to use all their skills, from counseling to developing resources. You do it all.

Susan Swinford
The Medicare Hospice Benefit was huge; before the Benefit we were providing mostly emotional support. Symptom management was in its infancy. People couldn’t afford their medicines and the cost of care would often bankrupt a family. For some, death was painful because patients could not afford the cost of the drugs. Once the Benefit became available, it lifted the burden of the cost of care and allowed the patient and family time to focus on the dying process.

The Benefit allowed us to develop professionally, write policies and procedures, and raise the level of patient care.
I got to help carve out the role of the social worker. Nurses were not familiar with what a social worker could do. I was able to advocate for patient self-determination and modeled how to hold family conferences.

Before the Benefit, hospice care was unregulated. The Benefit allowed us to develop professionally, write policies and procedures, and raise the level of patient care. We have been able to reach out and serve patients from all walks of life. When HIV/AIDS was inflicting so many individuals in our community, we were able to help. It was wonderful to be able to help so many families.

Looking ahead
Ms. Brown and Ms. Swinford had an opportunity to observe firsthand what it might have been like for a hospice patient in the early 1980s. Today’s hospice patient can expect better symptom management as well as care from well-trained professionals in an industry that is committed to improvement.

As we stop to look at the past, it’s natural to also look ahead. What can social workers do in the next 25 years? What needs to be done? How can services be extended to reach more minorities? How can we better educate social workers in end-of-life care? Will we have enough trained social workers to meet the need? What research needs to be done? How can we help the uninsured? What programs and services will be needed?

I am confident that social workers will continue to play an important role in the future as they strive to meet the needs of patients and families and join with other members of the interdisciplinary team to seek answers.

Sherri Weisenfluh has over 25 years of experience as a licensed clinical social worker. She currently serves as associate vice president of counseling for Hospice of the Bluegrass, a position she has held for 15 years. In addition, she teaches part-time at the University of Kentucky and serves as NCHPP’s Social Worker Section Leader.
Could Dame Cicely Saunders — who is credited with beginning the modern hospice movement in the 1960s — have imagined the transition of the hospice volunteer’s role? As she designed the interdisciplinary team meetings — that included volunteer physicians, nurses, psychiatrists, pharmacists, clergy and social workers — did she envision a time in the future when volunteers may no longer be invited to the team table?

Much of the work done in the early years of hospice was done entirely by volunteers and many of the first hospice programs in the United States — in areas such as New York City, St. Paul and Marin County — were begun by volunteers a decade or more before enactment of the Medicare Hospice Benefit. These volunteers used their community influence to bring in professionals and lay people who used their skills and experience to find the resources for medical care, make patients comfortable, alleviate pain as much as possible, and provide a positive presence for family members who were suffering in their own personal ways.

Hospice care in the 1960s and 1970s was totally funded by community resources. Volunteer work was a calling for a very few pioneers who could see...
what care at the end of life could look like. It was volunteer professionals who lobbied the Health Care Financing Administration for demonstration project grants to prove the value of hospice care, which led to the enactment of the Medicare Hospice Benefit in 1982, allowing reimbursement for hospice services and regulation of hospice programs.

To be a Medicare provider, hospice programs had to add structure to the role of the volunteer. A staff person had to be responsible for recruiting, screening, training and supporting the volunteer workforce. A percentage of staff hours had to be contributed by volunteers. Specific training on such topics as hospice goals and philosophy, protection of patient and family’s rights, family dynamics, and confidentiality were required. Skills beyond what an early volunteer might have possessed were developed and volunteers became more sophisticated in their support to patients and families. No longer could a volunteer just do the work they may have always done. Their role, in some ways, became the “extra” care and not as much a part of the team’s services.

During those early days of hospice, volunteers were coached to be all the patient and family needed. One volunteer would “adopt” a patient and, in many cases, become part of the family unit, providing bereavement care for family members after the patient died. In those cases, hospice volunteers were also essential members of the care team who collaborated with the nurse and social worker to provide the services and support the patient and family needed. Hospice staff knew the volunteers personally, communicating often about the patient’s status and grieving together when the patient died. Volunteers who have served patients and families through the 1970s and 1980s often share their stories about the fulfillment they received because they could see the difference they made in the lives of those who needed them in those final months and weeks.

Today’s volunteers
For the past decade, hospice programs have grown and are serving many more patients and, at the same time, hospice volunteers have become more specialized. Volunteer programs have 11th hour or vigil volunteers, bereavement volunteers, pet therapy volunteers, tuck-in volunteers, and the list continues. The programs are encouraging volunteers to learn new skills and to become proficient in distinct areas that support patients and families.

While many of these specialized programs are attracting new pools of talent, for some hospice programs there aren’t enough volunteers to cover each patient with a volunteer. Could hospice programs be losing volunteers because the volunteers themselves do not feel that they’re achieving the personal goals that prompted them to serve in the first place — of making a difference in the lives of others? Although specialization in volunteer skills is a good option for some people, are some volunteer programs becoming too focused on individual activities instead of engaging volunteers to be all they can for each patient and family? Would volunteer retention be stronger if, as in the early days, volunteers communicated directly with nurses, social workers and other team members rather than through their volunteer coordinators?

Where will hospice volunteer programs evolve from here? To provide the added value that comes from the work of the unpaid hospice team member — the volunteer — hospice programs will have to harness the energy of those individuals who have a calling to serve people at the end of life. No matter what the future holds for the Medicare Hospice Benefit, what will make the difference in the future of hospices everywhere is the hospice volunteer.

Kathy Roble has been director of volunteer services for The Hospice of the Florida Suncoast since 1994 and has been a frequent presenter at local, state and national conferences on topics related to volunteer management. In addition to her service as NCHPP’s Volunteer Management Section Leader, she serves on the education committee of Florida Hospices & Palliative Care, Inc.
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What do bifocals, ballpoint pens, and hospice have in common? They all evolved as a response to a need. Ben Franklin created bifocals so that he would not need to repeatedly change glasses. Ballpoint pens met the need to eliminate ink splatter and smearing. Hospice was created to meet a need for a unique kind of care at the end of life. Thus, hospice is distinctive from much of medicine which has evolved through scientific discovery and technological advancement.

This history is critical in explaining why and how hospices are called to provide “hospice palliative care”—end-of-life care dependent not on the election of a hospice benefit for payment, but on the need of the patient and family for the services which hospices provide. It is also critical to understanding how the provision of “hospice palliative care” is not in conflict with the Medicare Conditions of Participation.

The first hospice program in the United States was founded in 1974. By 1979, 26 established hospices participated in the Health Care Financing Administration demonstration project to examine the cost-effectiveness and desirable attributes of hospice care. With the passage of the Tax Equity and Fiscal Responsibility Act of 1982, the Medicare Hospice Benefit was created. Originally created as a three-year program, the Benefit was clearly set out as an informed choice for the terminally ill Medicare beneficiary. One fork led to the continuance of full Medicare coverage, unrestrained by any guiding principle other than what might be ‘reasonable and necessary for the diagnosis or treatment of an illness or injury.’ The other fork led to a hospice, a special kind [of] organization whose services were designed to be ‘reasonable and necessary for the palliation or management of a terminal condition’ and whose services would be provided by an interdisciplinary team with the goals and objectives of the hospice program in mind.

Furthermore, “the hospice program envisioned by the advocates and enacted by Congress was an intimate and very devoted one. It was a program that held itself almost aloof from the regular “curative” medical [sic] world and provided a unique context in which patients could use the understanding of impending death to make good choices about their remaining life — at home, among family members and friends.”

What does this mean for hospice palliative care today? First, history confirms that hospices based their original mission on patient and family needs, not reimbursement. As hospice care predates the MHB, it was hospices, not Congress, which authored hospice mission and philosophy of care. Congress created the MHB to pay for hospice care for people with a life expectancy of “six months or less if the illness runs its normal
course.” In doing so, Congress established the conditions for hospice remuneration, not the definition of hospice mission.

Second, to truly serve patients and families coping with the end of life, hospices will be called upon to help patients who cannot or do not choose to elect their MHB. Who are these patients?

Some of these patients are the ones more likely than not to live at least six months. (However, these are not patients who fail to decline, fail to meet non-evidence-based guidelines, or have already surprised everyone by outliving a six-month prognosis while looking too fragile to do so again; in these cases, remember that Congress accepts clinical judgment based on documented medical status as paramount.) A greater-than-six-month prognosis does not insulate patients with advancing illnesses from end of life fears, concerns, or need to plan. Hospice has the expertise — and should embrace the mission — to help these patients and families with symptom management, emotional support, spiritual solace, and advance care planning.

Other patients may have less than six months to live, but choose services “reasonable and necessary for the diagnosis or treatment of an illness or injury,” not services “reasonable and necessary for the palliation or management of a terminal condition.” This differentiation is becoming murkier as medical terminology and advances in medical treatments have clouded the distinction between “management of a terminal illness” and “treatment of an illness or injury.”

The terms “palliative” and “curative” have been used to signify this distinction. But we have no commonly accepted definitions of these terms, only convention. We don’t say cardiac bypass surgery is palliative, although it does not “cure” heart disease. What are we “palliating” with interventions that produce life-limiting side effects while decreasing disease presence by statistically significant (albeit clinically questionable) amounts? Are interventions “curative” or “palliative” if they might help a patient live longer, but still leave life expectancy painfully short? And, as we search for ways to serve patients and families sooner, do we really expect patients with a six-month prognosis to forego the same interventions as patients with a six-week or six-day prognosis?

Hospices have crafted tools and algorithms to help determine which interventions are “palliative,” help “manage the terminal illness,” and, therefore, are “covered” under the MHB. Such guidelines have included coverage when:

- evidence suggests interventions improve symptoms or function;
- interventions prolong life, but not beyond six months;
- pursuit of interventions supports the emotional well-being of the patient and family;
- interventions are consistent with a patient’s overall goals for comfort or quality of life.

But what do we say to Tom Hoyer who, in 1998 [as director of the Office of Chronic Care Policy at HCFA’s Center for Medicare Management], cautioned...
that questions about ‘coverage’ of services that may be both curative and palliative are often born of a lack of candor about hospice philosophy and the plan of care?\textsuperscript{8} Underscoring the viewpoint that the MHB was created to support home-based care, comfort, and support during a time of advancing illness that precedes expected death, he wrote:

[T]here is an increasing subset of providers who are dealing with this critical information issue by ignoring it and providing the curative care right along with the palliative treatment. Their reasoning, apparently, is that the patient shouldn’t have to lose anything; not the prospect of cure and not the prospect of palliation. It seems to me ... that this kind of thinking leads precisely to loss. The patient loses the chance to choose because there has been no chance to know.

Hospices cannot cover interventions and ignore distinctions between “curative” and “palliative” because they are difficult to draw or to discuss. In fact, it is only by talking with patients and families about interventions, their likely outcomes, and the coverage available under the MHB, that hospices protect a patient’s and family’s “chance to know.”

When patients do know, and then choose interventions beyond palliative management, are we obligated to abandon them? History and mission say no. Instead, our answer is hospice palliative care: care from an interdisciplinary team with expertise in symptom management and end-of-life concerns regardless of the choices — treatment or financial — that patients and families make.

In this 25th year of the Medicare Hospice Benefit, it is apparent that the recognition from Medicare itself has propelled hospice care from its “aloof” position to an increasingly integrated place in the medical care continuum. To be true to our origins, hospices will continue to evolve and grow to meet the needs of patients and families facing advanced, progressive illness and end of life.

Joan Harrold is medical director and vice president of medical services for Hospice of Lancaster County. In addition to serving as NCHPP’s Physician Section Leader, she is president of the Pennsylvania Hospice Network board of directors, a trustee of the American Board of Hospice and Palliative Medicine, faculty member for the NHPCO Physician Leadership Development Program, and co-author of the well-known Handbook for Mortals: Guidance for People Facing Serious Illness.

References:
5. Hoyer, p. 66.
7. NHPCO, pp. 33-34.
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When the Medicare Hospice Benefit was formulated in the 1980s, it required hospices to provide bereavement care to survivors for one year following the death of the patient. Since then, many community members and organizations have turned to hospice bereavement professionals for knowledge and support related to grief and loss.

More recently, hospices have taken a larger role in providing grief support to their communities in the aftermath of natural disasters and public tragedies. Events such as 9/11, the Columbine school shooting, and the Hurricane Katrina disaster have prompted many hospices to expand their basic grief support model for the loved ones of hospice patients to a larger model that provides grief resources and support to the community and the nation.

What to look for
Survivors of natural disasters and public tragedies typically display a range of emotional, physical, and cognitive reactions in the aftermath of the event. These reactions vary greatly, influenced by proximity to the event, available support systems, the survivor’s prior psychological functioning, cultural norms and values, and the survivor’s perceived ability to receive assistance. Generally, the more one is affected by the event, the stronger the reaction.

Typical emotional reactions include shock, grief, and anxiety. The focus is on the well-being of oneself and loved ones, and the protection of possessions. There may be relief for having survived and avoided injury, anger at the forces of nature or at the perpetrators, or guilt at being unable to help loved ones.

Typical cognitive reactions include confusion, indecision, difficulty concentrating, forgetfulness, and flashbacks. Physical symptoms can include headaches, fatigue, and changes in sleeping and eating patterns. Common interpersonal reactions such as conflict, distrust, withdrawal, and sensitivity often occur. Generally these symptoms dissipate at some point after the event, with each individual’s reaction and recovery timeframe being unique.

Severe reactions to a disaster may require immediate attention by a professional who is trained in post-traumatic stress response. These symptoms include intense, continual re-experiencing; denial of the event; terrifying nightmares or flashbacks; hypersensitivity; extreme anger; disassociation; panic attacks; severe depression; and substance abuse.

Deaths resulting from natural disasters and public tragedies are generally unexpected and traumatic, and may lead to higher risk of bereavement complications for survivors. If the bereaved person is unable to see the body of the deceased, if there are concurrent life stressors related to the tragedy, or if the survivor is vulnerable due to factors such as mental illness or substance abuse, there may be complications.

Crisis intervention is specialized
The kind of training hospice bereavement personnel receive does not generally include techniques for traumatic stress response. Some organizations that do provide professional crisis intervention include:

- American Red Cross (RedCross.org)
- International Critical Incident Stress Foundation (ICISF.com)
- Association of Traumatic Stress Specialists (atss-hq.com)
- Salvation Army (salvationarmy.usa.org)
- National Organization for Victim’s Assistance (trynova.org)
Individuals trained to respond immediately to a crisis address the most immediate, basic survival needs. They are a calm presence, allowing for expression of emotions and thoughts associated with the event. They also educate regarding the emotional reactions to anticipate, thus helping those affected to plan for the future. Critical Incident Stress Management debriefings often occur 48–72 hours after the event, but in a larger incident they may take place much further out from then, as responders continue to be involved in the incident response.

Many people cope effectively with the emotional and physical demands brought about by a public tragedy or natural disaster by relying on their own support systems. For others, however, serious problems continue to interfere with activities of daily living. Individuals experiencing ongoing issues should consult a trained and experienced mental health professional, who can explore common responses to extreme stress and help people find constructive ways of coping.

Responding to the aftermath
Some hospice professionals are trained in providing crisis response. In Pennsylvania, at Hospice of Lancaster County’s PATHways Center for Grief & Loss, the bereavement counselors have taken ICISF (International Critical Incident Stress Foundation) training. Two staff members serve on the executive board for the county Critical Incident Stress Management (CISM) team. In fact, the PATHways Center hosts the CISM board meetings and team trainings.

Given this relationship, Hospice of Lancaster County was actively involved in the recent Amish school shooting. The CISM team — along with the PATHways Center’s staff — was there from the first day. Patti Homan, director of the PATHways Center, said “I believe we have been able to be an integral part in the ongoing support because we were involved from the beginning.”

In the weeks and months since the tragedy, Amish and “English” — the word the Amish use to describe anyone outside of their community — have participated in several of the community counseling sessions PATHways has provided. PATHways also collaborated with other organizations to provide education and resources to the community.

Reaching those at a distance
Individuals at a distance from the site of the disaster or tragedy may experience some of the same emotional, physical, and cognitive reactions as the event’s victims. It is common to experience survivor’s guilt and, at the same time, feel relief at being spared. Those at a distance often report feeling more vulnerable and anxious after witnessing a disaster.

Nancy Sherman of the Center for Grief and Healing at Hospice of the North Shore in Danvers, Massachusetts, notes, “We have carved out a niche providing education in the media after a disaster. In this way, we reach people who are helped just by virtue of reading about what to do, what to expect, and how to care for others after the event.”

continued on next page
Individuals and communities not directly affected by the event, including hospices, may experience overwhelming sympathy and yearn to help the victims. Given the nature of their work, many hospice professionals are adept and committed to helping those in need. Hospices are generous in responding with in-kind donations and services during natural disasters and public tragedies.

During the Katrina disaster, hospices from all over the country flew staff to the Gulf area to assist with the relief effort. Dr. Jay Peitzer, a physician with VITAS Innovative Hospice Care® of Broward County, Florida, spent 18 days in Mississippi with the Florida Disaster Medical Assistance Team, treating more than 1,300 evacuees. NHPCO also reports that hospices in the New Orleans area and around the country responded to Katrina with supplies, personnel, and money.

**An ongoing resource**

Hospice bereavement professionals can be most helpful in responding to the long-term grief effects of public tragedies and natural disasters.

“There some years ago there was a terrible train collision outside of Washington, DC,” recalls Larry Crawley-Woods of Hospice of the Panhandle in West Virginia. “Several local Job Corps students were killed. I was part of the team that went on campus to meet with students for counseling and consultation. In the aftermath of a tragedy, our role is more of an ongoing resource for people.”

Paul V. Johnson from HealthPartners Hospice of the Lakes adds, “I have been asked to speak with local businesses and schools when there has been a death of an employee, teacher, or student. We don’t publicize that we are available for that kind of support. Requests to become involved just seem to find their way to us!”

One example of extraordinary hospice support took place in August 2006 when Comair Flight 5191 crashed on takeoff from Blue Grass Airport in Lexington, Kentucky. Hospice of the Bluegrass, also in Lexington, immediately partnered with the Red Cross, city government and several corporate leaders to provide assistance. Hospice staff provided one-on-one support to community members, visited the crash site with families, assisted with memorial services, provided support in several workplaces, offered drop-in support at their grief center, and provided grief education through various media.

Hospice of the Bluegrass continues to provide long-term grief support for the families of those who perished in the crash, support that is sponsored by Care Fund through the United Way. The hospice has created specialized materials and services for the families (both local and distant) that included forming a family-led advisory committee, providing a memorial service on the one-year anniversary, facilitating a holiday grief support group for survivors, and offering individual and family support sessions.

The United Way wrote in a press release:

> Through extensive national networking, hospice can provide assistance to families both here in the Bluegrass, and nationally. Crisis response services were extremely helpful after the disaster. The need for grief support continues much longer, however. Hospice recognizes that grief is very unique and that what one individual finds comforting and helpful another may not. It is also difficult to put a timeline on someone’s grief.

**Hospice is still there**

People directly affected by an event need to tell their story: what happened; what they felt; how they reacted. It can be difficult for others who are suffering to listen and be supportive. At some point, the emergency response crews go home and media attention dwindles. Survivors are left to put their lives back together and deal with complex personal and bureaucratic issues.

Attentive listening by a hospice team member can help offset feelings of isolation, frustration, and weariness, as can participation in a support group. Learning about the spectrum of grief responses from a hospice bereavement educator can help normalize grief and allay victims’ concerns about how to grieve. Bereavement educators can provide tips on journal writing, caring for oneself, and other ways to manage grief.
Survivors of natural tragedies seek spiritual support as well. Spiritual convictions are often shaken as a result of a public tragedy or natural disaster. People question how something so horrific could have happened. Individuals seek strength to persevere and move forward as they face new uncertainties. They search for meaning in a way life has changed. With the spiritual support of a hospice team member (particularly a chaplain), these feelings of spiritual distress and confusion can be expressed.

It is common on the anniversary of the tragedy for individuals to experience an “anniversary reaction.” Memories come flooding back. Individuals reexperience the emotions of that day. The first anniversary is generally the hardest. Like Hospice of the Bluegrass, we can be instrumental in memorializing common losses on anniversaries through gatherings, support events, etc.

Certainly these examples stretch far beyond the basic Medicare requirements of providing grief support to hospice survivors. Involvement at any point after a natural disaster or public tragedy clearly fulfills the NHPCO Standard of providing “bereavement education and supportive services to the community at large.” (BC 5.5) With the priority on meeting hospice patient and family bereavement needs, many hospices play less of a role as “first responders” to a natural disaster or public tragedy. Most, however, play an important role in providing support, resources and education on grief during the long aftermath. As Marcia Lattanzi-Licht eloquently states in Living with Grief Coping with Public Tragedy: “Supporting people is a counterbalance at a time of tragedy... (as it) prompts us all to remember that we may not have control over violence in the world, but we can respond with integrity and compassion to heartbreaking situations... There is a seat for us at the table as creative partners surrounding the human responses to tragedy.”

Robin Fiorelli has worked for VITAS Innovative Hospice Care® since 1993. Prior to becoming senior director of bereavement and volunteer services in 2003, she held positions as a medical social worker, team manager and bereavement services manager. A licensed clinical social worker by training, Robin presents frequently on grief and healthcare-related issues throughout Texas and California, and is the author of Living with HIV: Resources for Women and Children in San Francisco County. She is currently writing a chapter on children and grief for a book on the effects of loss and death on health to be published by the University of North Carolina Press.

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A Direction for the Future

By Richard Briggs, MA, PT

The first 25 years of existence has been a time of considerable growth and change, for us as organizations and therapists specializing in end-of-life care, and as individuals. We look back to see where we began, assess where we are now, then project how we might develop further.

“The future belongs to those who prepare for it today” — Malcolm X

The visionary designers of the Medicare Hospice Benefit recognized the value of the rehabilitative therapies, and included physical, occupational, and speech therapy as covered services as needed during hospice care. They realized that, at that time, no hospice organization met the new standards, but all could work towards achieving this level of excellence in service. In that year, 1982, Dr. Jane Toot of Northwestern University submitted the first professional article for publication in the journal of the American Physical Therapy Association (APTA). While outlining the tenets of hospice, she raised questions about the role and education of therapists who would be needed to provide interventions with this new approach to care. Since then, different models of practice for physical therapy have been developed across the palliative care and hospice spectrum. As recently as 2006, the APTA has formed a special interest group for physical therapists specializing in this niche of clinical practice.

At the close of a physical therapy evaluation, a patient asks, “Would you walk me to my grave?” The therapist replies, “I would be honored.”

Similar developments have occurred in occupational and speech therapy professions. The emphasis on quality of life as directed by Dame Cicely Saunders — ‘that we will do all that we can not only to help you die peacefully, but also to live until you die’ — underscores the role of rehabilitation in supporting the dying in their living.

‘Recreational eating’ can be explored and taught to patients and families for enhanced quality of life by a hospice speech therapist.

Beyond the rehabilitative therapies prescribed by the Medicare Hospice Benefit are the expressive art and music therapies. Board certified professionals have become integral to the care provided by many hospice teams. Using these unique and often metaphorical media, expressions of an enormous range of human emotions, memories, and visions can be brought into the realm of awareness for the patient, their family, and the hospice team members. Recent research documents the effectiveness of these interventions in satisfaction with end-of-life care. In this realm, we have progressed from the general sense that this therapy would be helpful to evidence-based practice, the highest standard for care.

‘Drawing nearer to God,’ are the words art therapist Barbara Trauger-Querry at Hospice of the Western Reserve (Cleveland, Ohio) uses to capture the experience of some as they process the end-of-life experience through art therapy.

Complementary therapies such as massage, Reiki, and aromatherapy have been used for thousands of years to comfort those with illness. As such, these practices have also come to be integrated into what is recognized as quality end-of-life care. While these therapies were initially offered by volunteers — and continue to be in many programs — there is a developing movement towards hospice professionals integrating these skills into their practices.

A scent can bring about remarkable changes in awareness, memory, or emotion.

Holy Redeemer Home Health and Hospice (Philadelphia, PA) has several clinical positions for Complementary Therapy Registered Nurses (CTRNs). These practitioners use either medical interventions or their certified training in bodywork such as massage, Reiki, reflexology or...
Healing Touch, to provide comfort and symptom relief. Their work is a model for the highest integration of traditional and complementary care. They also teach families to use either approach in their care for loved ones.

"Where touching begins, there love and humanity also begin”
— Ashley Montague

Where have we arrived in our maturation process? An informal survey shows that individual hospice programs across the country have unique degrees of maturity and utilization of the different allied therapy disciplines. The reasons for this may vary from agency size... to proximity, therapist training institutions, experience, and philosophy of staff or leadership. This inconsistency leaves the public with incomplete and not fully available services in end-of-life and bereavement care.

"If you don’t know where you are going, you’ll wind up some place else”
— Yogi Berra

Making the highest level of therapy available in each of these disciplines needs to be the goal of every hospice organization in the next 25 years. Having one or two therapy disciplines will not be sufficient, nor will minimal utilization. There are a growing number of specialists in each therapy discipline, trained and capable of providing palliative and hospice care. When full and comprehensive therapy participation occurs as part of the interdisciplinary team, we will be able to address each patient and family situation with the complete array of team support to best guide their passage through the completion of care. This is the standard towards which we must strive.

Richard Briggs has 20 years of experience as a physical therapist with Enloe Homecare and Hospice. In addition to his role as NCHPP’s Allied Therapist Section Leader, he writes, lectures, and consults with agencies to integrate physical therapy into hospice care through his practice, Hospice Physical Therapy Associates.

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The conference is being held in Washington, DC, April 19-21. For details, visit nhpco.org/MLC2007.
Building Beyond the ‘Box’
By Brenda Olcott, MBA

From its charitable beginnings sparked by a few individuals, hospice has grown both as a dynamic movement and a medical institution. Today, more than 4,000 hospice organizations in the United States care for over 1.2 million patients and their families annually. Today, hospice involves and unites thousands across cultures, geographies and socioeconomic levels with the vision that all people deserve dignity and comfort at the end of life. As the market we serve — a market which includes all people — grows and becomes more sophisticated, so must our approach to developing hospice beyond the hospice Medicare “box.”

An estimated 75 to 80 percent of U.S. hospice organizations are Medicare-certified. Through the Medicare Hospice Benefit, CMS establishes both reimbursement rates and the Conditions of Participation every program must meet. The Benefit fosters an environment of accountability and consistency, creating the parameters or “box” within which the majority of hospice programs operate. The strength and benefit of this box is that the Benefit makes the hospice mission to provide care a societal entitlement, by which all individuals can expect and receive quality care at the end of life. While the Benefit overflows with challenges and opportunities, it lays a solid foundation for the future of hospice, a future that will flourish if we view the Medicare Hospice Benefit as a building block and not as a box.

As hospice organizations contemplate the future, they foresee a constantly changing landscape. In the coming years, more people are expected to access hospice care. Families will be more geographically dispersed. Nurses will be in short supply. The costs of hospice services are expected to rise while hospice Medicare reimbursement rates are not expected to keep pace with escalating operational costs. Forward-thinking hospice development, marketing, and public relations professionals are being challenged to help their organizations build a future upon the Medicare box and not within it.

Ongoing challenges for hospice are to increase access to all who would benefit from our services, broadly spread awareness, and meet future demands responsibly and effectively. For development professionals, this challenge includes increasing non-Medicare revenue streams to cover the difference between operational costs and reimbursement rates. For marketing and public relations professionals, this challenge requires diligent stewardship of the hospice mission, spreading awareness to people of all ages, dispelling the myths of hospice, and increasing the knowledge that a “good death” is both possible and accessible.

How can this be accomplished? Hospice professionals will need to think and act creatively and move away from the “business as usual” approach. The successful development, marketing and public relations professionals will be the ones helping their organizations capitalize on their
core competencies while reinforcing the value of their programs in the minds of their various publics, including policy makers, physicians, donors, volunteers, staff and potential clients.

Strategically breaking down boundaries and thinking outside the box requires hospice providers, both globally and locally, to see beyond the preconceptions and self-imposed boundaries that keep us from innovation and growth. From advocacy to broadcasting, the future is dependent on our collective ability to creatively promote and shape public perception of hospice. This means our efforts must focus on reaching out to every individual and every audience — from celebrity endorsements, government lobbying, and multilingual grassroots education to consistent utilization of hospice campaigns, such as NHPCO’s “It’s about how you LIVE,” and relationship building with the media, physicians, schools, care facilities, politicians, and the general public.

To successfully “build on the box” requires solid outcomes-oriented marketing, taking into account segmentation, targeting, positioning, product, pricing, placement and promotion. While the Medicare Hospice Benefit helps programs define product and pricing, the remaining elements depend on our understanding of the market we serve.

Hospice development, marketing and public relations professionals should consider how to engage their boards and volunteer leadership in the endeavor. For example, involve your board-level Public Relations/Marketing Committee — which should include non-board marketing and public relations professionals from the community — in the planning and implementation of your organization’s marketing strategy. Clinical staff should also be incorporated into your public education and marketing efforts. More research could be initiated into the needs and expectations of the various segments of the hospice market, as well as into the kinds of messages and communication channels to which these market segments most readily respond.

Viewing the Medicare Hospice Benefit as a building block transforms the “box” into a foundation for growth and success. While it may often seem like a high-wire balancing act, treating the box as an opportunity allows hospice programs to reach beyond comfort zones—and this is where we’ll discover new ways to expand and explore future opportunities.

As legislators and programs strive to address the growing healthcare needs of our nation, along with increased demands for access to quality care, the promotion of hospice is imperative. The disciplines of development, marketing and public relations are dependent on the quality of care all programs offer and the awareness of what hospice is and does. The opportunity to work together to create the vision of hospice in the present and the future is not contained in Medicare guidelines, but in the people who deliver care, who work beyond the box, and who tell the story of this essential, compassion-filled part of the healthcare system.

Brenda Olcott is the public relations and education manager for Hospice of Hilo in Hilo, Hawaii. She joined the hospice in 2004, following a career in business consulting and customer relations management.
Good to Great
Another Look at These Important Principles
By J. Donald Schumacher, PsyD

In the acclaimed publication, Good to Great, author Jim Collins outlines his findings about companies that made the leap from good to great and sustained those results over time. Good to Great provides insightful models for anyone interested in building organizational excellence. Collins offers organizations a practical framework that focuses on commitment to excellence and the importance of leadership.

As we take time to reflect on the 25th anniversary of the Medicare Hospice Benefit, it’s just as important that we pay attention to the next 25 years and beyond. The concepts and principles explored in Good to Great have significant resonance for us, particularly as we stand at the doorway of our future. Some of you are familiar with Collins’ work, others are not. Either way, I want to touch upon Good to Great and offer some thoughts, not only from my position here at NHPCO, but as a former CEO of a hospice organization for more than 20 years.

The Social Sector
While the case studies in Good to Great are major companies from the business sector, I have always maintained that the principles Collins discovered in researching great organizations logically apply to the social sector. I think Jim would agree with me. In fact, in 2005 he published a monograph to complement the original text, Good to Great and the Social Sectors.

Good to Great and the Social Sectors reflects on the framework for greatness that Collins lays out so clearly in his work. What is helpful about this monograph is that it connects some of the dots for those of us who are working in the social sector. (I want to mention that Jim originally intended his work on the social sector to be a new chapter in Good to Great, but after some thought decided he didn’t want people to have to purchase a new copy of the book to get this additional insight. I encourage those of you with this bestseller on your bookshelf to add the monograph as soon as possible.)

Good to Great offers nine enduring principles common to organizations that achieved and sustained greatness over time. In the monograph, Collins synthesizes his familiar principles into five issue areas important to greatness in the social sector:
1. Defining “Great”
2. Level 5 Leadership
3. First Who — Getting the Right People on the Bus
4. The Hedgehog Concept
5. Turning the Flywheel — Building Momentum

It would be a disservice to Collins to summarize these principles within one brief article — that’s why he wrote the book. But I want to add some comments that I hope are useful to those of you who know his work, and intriguing to those who have yet to learn about it.
Enduring Principles
In thinking about the nine enduring principles or the five issue areas, it’s a mistake to think that they are in a hierarchal order. Yes, there are initial steps and foundational work that must be put into place in the early stages of an organization’s journey to greatness — “first who and then what” is a phrase that will be familiar to Good to Great readers — but Collins reminds us that the principles coexist and reinforce one another. It’s not “principle one” and now “principle two” and then “principle three” etc...but the principles/issue areas must be integral to all decisions made and to all the work done at every level within an organization.

I hope those of you familiar with NHPCO’s Quality Partners will recognize a similar philosophy. The 10 components that make up Quality Partners are not in a numbered order, but coexist together. This design was intentional. Different organizations will focus on different components at different times. Ultimately, every single component is important to a great provider. The components should not be thought of as tasks to complete so you can move on to the next one. They are integral concepts and principles that should be very much alive within an organization on an ongoing basis.

Is it easy to maintain this focus and level of accomplishment? Absolutely not; that’s why Collins focuses extensively on discipline. One of the metaphors Collins uses in his exploration of sustained greatness is an image of a flywheel — and discipline is a fundamental component of the flywheel.

Discipline of the Flywheel
While I’m simplifying a bit, bear with me and envision the following in your mind: To get that flywheel turning in the beginning, an incredible amount of work is required. As a flywheel turns, momentum builds and builds, eventually reaching a level of speed and productivity that belies the effort used to initiate movement. You don’t stop working to keep the flywheel moving, you maintain your efforts, but momentum continues to increase. Collins describes the flywheel as a cumulative process made up of individual steps, actions, and decisions that lead to sustained and spectacular results.

The ongoing momentum of the flywheel is an image associated with great organizations and one that many of us would like to envision for the futures of our organizations. Collins maintains that without discipline, the flywheel will never build the momentum necessary for sustainability. A simplified overview of the Collin’s flywheel premise in Good to Great might best be summed up by the author himself:

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Disciplined People
Disciplined Thought
+ Disciplined Action
= Sustained Greatness
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Collins writes, “Greatness is not a function of circumstance. Greatness, it turns out, is largely a matter of conscious choice, and discipline.”

continued on next page
One-on-One With Jim Collins

About a year after I became president/CEO of NHPCO, I had the opportunity to visit with Jim Collins at the author’s office in Boulder, Colorado. We discussed the ways that his research had application to hospice and palliative care providers. (Jim’s family had a positive experience when hospice helped during his mother’s death.) An ongoing theme in our discussion involved the “why” and the “how” of what we do. Why we do the important work we do should remain at the heart of our mission. The why contributes to our core values and will always be important to us as organizations and professionals. How we do that work must be open to change and adaptation.

Let me share one of Jim’s comments:

When I look at hospice I think of it as why you are here, making the process of dying a fully human, engaged process that in and of itself has its own redeeming value, for all the persons concerned. It’s about the web of relationships. That’s why you are here. What you do may and should change. One of my challenges for hospice is to be really clear why you are here, and what the few guiding values are that form the framework. But what you do and how you do it — the practices, the mechanics, the implementation — have got to be open for a lot of change.

I need not tell you that we, as human beings, tend to shy away from change and can be overly cautious about things that are new. That’s not necessarily a bad thing. However, if our fear of change prevents us from responding to the needs of those we serve or prevents us from fulfilling our true mission, we have a problem. This is why the work of researchers such as Jim Collins is so valuable to us. It provides a framework to guide us through our ongoing journey.

Collins’ principles are not the only model organizations might find familiar. Another valuable model is that of Prescriptive Leadership as developed by the Studer Group and practiced by our colleague Dale Knee, NCHPP CEO section leader and president/CEO of Covenant Hospice. (Dale will be sharing some information about the Studer model in a future issue. For now, I appreciate the opportunity to continue to reflect upon Good to Great.)

Three Circles

As part of our exploration together that afternoon in Boulder, Collins suggested that hospice and palliative care providers and professionals must set goals and strategies based on an understanding of how the “three circles” explored in Good to Great relate to hospice and its core:

- What can we be the best in the world at?
- What do we feel passionately about?
- What drives our economic engine?

The passion question is one that many of us in the social sector are comfortable with. Likewise, most of us know what we can be the best in the world at. (Remember, it’s what we can be the best in the world at and not what we want to be the best at.) There are a number of leaders in the hospice sector, however, that get tripped up by the concept of an “economic engine.” In his new monograph, Collins rephrases this question to be: What drives your resource engine? This is a subtle yet helpful adjustment for many of us.

To think of our resource engine solely in terms of financial transactions is a problem. What we need to understand is how to develop a sustainable resource engine that enables us to continue working on our mission and keep that flywheel going. This requires that we examine and understand all aspects of our organizations and how they function, particularly the difficult issues.

The Brutal Facts

Collins spoke of the importance for organizations to acknowledge the “brutal facts” in front of them. You cannot make a series of good decisions for your organization without first confronting the brutal facts.
The brutal facts that hospice and palliative care providers must confront, as Jim sees them, involve growing competition, periods of unresponsiveness — real or perceived — to the patients, families, and clients who are served, and the benefits and burdens of the Medicare Hospice Benefit.

Interestingly enough, many people in the field who are uneasy about the economic engine circle are the ones very uncomfortable with Collins’ comments surrounding the Medicare Hospice Benefit. Given our attention on the 25th anniversary of the MHB, it seems fitting to share some of his thoughts regarding the Benefit. I should point out that Collins’ comments are intended to initiate rigorous thinking, so keep that in mind:

I think one of the biggest brutal facts facing this industry is that it got the Medicare Benefit...It allows you to be intellectually undisciplined about connecting all three circles together. You do not need to make the connection between how all the three circles work so long as you’re staying within the parameters of what qualifies for a Medicare payment. Regardless of whether the whole holistic circle is working, there’s an economic exchange. That is not rigorous thinking.

Rigorous thinking is to look at it as: We understand there’s a relationship between the passion circle and the best at circle and the economic circle. And we understand our economic denominator in a way that drives results over time in a very sustainable way. The presence of this big thing called the “Medicare benefit” distracts from the rigor needed to create that.

I would challenge hospice to figure out how to make its economics work such that you can take it or leave it on the Medicare benefit...I’m saying that you use it as a thought experiment — to really think it through. I’m not saying it would necessarily happen or it would be altogether advisable, what I’m saying is its presence allows you to be sloppy.

The Medicare Hospice Benefit is an important part of our industry and it will continue to be. What we are challenged with is thinking about integrating the Benefit as a component of our resource engine. Reliance upon the Medicare Benefit as the sole payor prevents us from the rigorous thinking that research has shown is present in historically successful organizations.

As I continue to think about what Jim Collins is saying to us, it goes beyond reimbursement and our economic engine. If we are to follow his suggestion to work through issues relating to the Medicare Benefit as a thought experiment, it brings us right to issues of quality. As we explore what the ideal resource engine might be for hospice providers, there’s no way we can get around issues of quality — they are implicit in any model of sustainability.

I strongly believe that we must celebrate our past while we simultaneously look towards our future. I drive pass the National Archives building on trips from NHPCO’s office to Capitol Hill. Carved on the beautiful stone exterior is a quote that always gets me thinking, “What’s past is prologue to the future.”

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Our past provides the insight and skills and understanding we need to tackle challenges of the future. But we must be open to adaptation and change.

The world around us is changing; it’s critical that we don’t allow our industry to fossilize. There was a time, not long ago, when it would have been inconceivable that the American automotive industry would be anything other than a global industrial leader, free from any threats to its success. Few people from a generation ago would believe the challenges facing the U.S. auto industry today.

There is no question that we can respond to the changing needs of the world around us and to the patients, families, and communities we serve. We must, however, make a commitment to quality, education, assessment, improvement, and collaboration. These ideas are integrated throughout many of our professional development offerings, like Quality Partners, the Hospice Manager Development Program, the audio web seminars, and our annual conferences and educational programming. In order for these programs to work, and help us achieve levels of greatness and sustainability, we must work together as the collective body and voice of hospice and palliative care.

Twenty-five years ago, when a number of visionaries and pioneers were making history by changing the care people receive at the end of life, they might never have imagined the amazing success and accomplishments we’ve all seen and been a part of. With such an exciting prologue, I look forward to the many achievements in our future.

J. Donald Schumacher joined NHPCO as president/CEO in 2002, and shortly thereafter was also appointed president/CEO of NHPCO’s two affiliate organizations: the National Hospice Foundation and the Foundation for Hospices in Sub-Saharan Africa. In addition to his service at the national level, Dr. Schumacher was president/CEO of The Center for Hospice and Palliative Care (Buffalo, NY) from 1989-2002, and president/CEO of Hospice West (Waltham, MA) from 1978-89. He was also the founder/president of one of the country’s first HIV/AIDS hospices, The Hospice of Mission Hill in Boston, MA.
Strategies for Success:
A Conversation With John Kenagy

John Kenagy, MPA, MD, ScD, FACS, is a person of many talents. While he has 30 years of experience within the healthcare field — having worked as a vascular surgeon, healthcare executive and researcher — his experience as a patient was the turning point in his career. That experience opened his eyes to the ineffectiveness and inefficiency of the current medical model and took him to Harvard Business School, where he served as visiting scholar from 1998-2002. During his tenure at Harvard, he studied those companies which were able to excel within complex and unpredictable industries, and formulated his own strategies for success.

The end-of-life field is now at a turning point in its history. As we evolve and expand, how do we ensure that we continue to grow the right way? That we preserve the spirit of innovation that brought us where we are today? At NHPCO’s Management and Leadership Conference this past September, Kenagy shared some of his strategies during his plenary, “Designed to Adapt: Quality, Hospice and the Future of Healthcare.” Recently, he met with Don Schumacher, at our office in Alexandria, VA to explore this topic further. Here are excerpts from their interesting exchange.

Don: I think we both agree — or as baby boomers should I say concede — that our country is entering the ‘golden age’ of dying and that end-of-life care has become a great growth industry. Having analyzed the downfall of some industry leaders, what advice would you offer hospice providers at this key juncture?

John: Certainly, dying is becoming more attractive from a traditional business point of view. The more people who die, the more interested people are going to be in the business of dying. It has everything to do with the numbers game. Growth markets are always attractive to people who want to make profits. That being said, the hospice field is going to be a target.

My advice to hospice providers is, first, to realize that you’ve had the advantage of working in an area where no one wanted to work before, that you’ve had the luxury of competing against non-competition. But, while nobody else has been in your space, they are going to be — and it’s going to get crowded. And your competitors will attack your business in two ways: They will try to perform better than you do — and they’ll be highly incented to perform better because they want a position in this growth market. And they will try to move into a space that you don’t yet occupy or one that is not, on the surface, particularly attractive to you. This latter threat, could become what I have termed Adaptive Innovation. This is what you should be most alert to in a competitor. You already have a big advantage on performance and if you stay on your toes, your expertise will keep you ahead of the curve. The much bigger challenge for you comes from those who will try to move into a space where you are not.

Don: Based on your observations, in what areas do you see this occurring?

John: It always starts with unmet needs. For example, I think the unmet needs of some racial cultures in this country would clearly be one area. As hospices already know, many cultures have a different view and understanding of death and dying, have different spiritual needs, and have a different family dynamic. Also, many are separate and apart from the mainstream community geographically. So an organization...
which meets the needs of middle-class white Americans very well might have difficulty meeting the needs of other racial cultures — and not necessarily because those cultures are not open to the hospice approach. It may be that they’re just not open to the context in which it is offered. Thus, another competing organization may be much more capable of delivering ‘in that space,’ having been developed and and improved in that space. It’s both the access and the ability to customize services to meet these unmet needs that could be very difficult for an established organization, with a set way of doing business, to compete with.

But, what is a threat can also be an opportunity to extend your current skills and capabilities into new markets. I think hospice leaders should strive to be alert to their community’s unmet care needs – especially needs that may be ‘off the radar screen’ of their competitors — and find ways to expand their services into those places. All the great Adaptive Innovations have evolved in this way. That is, not just jumping into a new service, but adapting the service you already provide to a new space, to an unmet need. And if you look at healthcare, there are so many unmet needs to fill. There’s a cornucopia of opportunities. For example, I think chronic disease management is an area in which hospices could excel. Traditional healthcare does not manage chronic diseases well right now. Since hospice has a unique skill set to work with patients and families in the outpatient environment — that no one else really has — this is certainly an area ripe for adaptive expansion.

Don: Can you cite an adaptive innovator which has succeeded in overtaking an established market?

John: Southwest Airlines is a good example of an adaptive innovator. They started small with a fundamentally different, low-cost business model — different methods, structures, and value systems than traditional airlines. They did not reinvent themselves; they ‘reinvented’ the airline industry by having the vision and discipline to grow that business model and not try to emulate the successful practices of the traditional airlines. The leaders like United, Delta, and American tried to copy Southwest but failed because established organizations find it extremely difficult to change methods, structures and value systems. Viewed through the lens of Adaptive Innovation, the change and turmoil in the airlines, in healthcare, and in many other industries is not only understandable, it is completely predictable.

Don: I was struck by your comment that all great organizations start by doing things for people — meeting unmet needs with simple technology and functionality. But as these organizations become well established, they also become “hospitalized.” What do you mean by that?

John: ‘Hospitalization’ occurs as healthcare organizations become larger and develop separate managerial hierarchies in which the ‘experts’ on the management team tell the workers what to do. I call this the “Traditional Business Enterprise” – a powerful, effective business method and structure developed during the Industrial Revolution of the 19th Century. It works great when the work is understandable and predictable. But, in today’s complex, dynamic unpredictable world it often distances organizations from their customers. We at Kenagy & Associates believe that the successful organizations of the future
will be the ones that adapt, develop, direct and coordinate the knowledge, creativity and problem solving ability at the frontline — that is, where the action is, where the value is being added. In hospice, the IDT concept and the focus on the patient/family’s plan of care are your greatest strengths. You’re already ‘focused’ in the right way. Your challenge will be to adapt current structures and methods to keep doing and improving what you are now doing right — in new spaces. Again, that’s being an adaptive innovator.

**Don:** How can a hospice or palliative care organization develop the skills to adapt?

**John:** The “how to do it” is always the big question. In looking at companies which have been successful at doing this, we believe direct observation of the actual value-adding work is key. This is especially true for hospice organizations, since your services are provided in many care settings. Direct observation can put you back in touch with what your customers really need, something companies can easily lose sight of as they grow and become “hospitalized.” Let me give you a couple of examples.

I observed an intake not too long ago where the hospice nurse did a wonderful job of providing a comprehensive overview of all the services her organization could offer. As the nurse was leaving, the patient stopped her, seemingly embarrassed to say he did have one question. ‘Is hospice going to take all of my savings to pay for this?’ he asked. ‘I heard that it will.’ That patient almost didn’t ask the question, but aren’t we glad he did? A CEO from another organization, quite large as I recall, shared another example. She said they have always been very proud of their impressive list of services, but found some real perspective after meeting with one elderly female patient. They quickly learned that her primary concern, after hearing about all they could do for her, was how she was going to clean behind her refrigerator. She had been too ill to clean back there for the past three months.

It’s that ability to really understand the job we’re being asked to do that will help us succeed going forward. Those patients’ questions and concerns are an important reminder that we may *think* we know what a patient needs and wants, but we may have it all wrong. While hospice work involves complex issues, it is still instructive to always ask yourself two fundamental business questions: How do I know when I have not delivered value? And how quickly can I resolve that problem? To help management answer all those “how” questions, we have developed Adaptive Design® to provide the direction, skills and tools organizations need to be continually innovative.

The problem is as companies get bigger, they start to change their value proposition and they start to think about all the other things they’re doing. This is dangerous. Understanding specifically how you add value is critical. Who is the customer? Who are we providing services for? And what value do we offer — how do we know the job that we’re being asked to do is getting done? What do we do when it’s not? Because management of a large organization can’t be every place all the time, Adaptive Design helps leadership know when staff is constantly asking those fundamental questions and problem solving when current systems fail to deliver.

**Don:** Are there some resources you can recommend as further reading?

**John:** Actually, using Adaptive Innovation and Adaptive Design in the context of hospice is quite new territory. With little written about it, your programs will be ahead of the curve as we explore it together. The article I co-authored for the Harvard Business Review, however, is a very good start [“Will Disruptive Innovations Cure Health Care?” Sept/Oct 2000]. Your members will be able to identify with the examples cited in that article even though hospice isn’t specifically referenced. I also think my two-day preconference session at MLC this April will provide some valuable tools for those who are able to attend.

To access the Harvard Business Review article, visit the Web site of Kenagy & Associates ([kenagyassociates.com/ready.php]). To learn more about John Kenagy’s two-day preconference intensive at MLC, visit nhpco.org/MLC2007.
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Workforce Excellence
Hospice’s Most Valuable Resource

In this month’s Quality Partners column, we take a closer look at the sixth component of the initiative’s “10 Components of Quality in Hospice Care.”

The provision of quality hospice care is utterly dependent on the quality of the people who deliver it — the health professionals, paraprofessionals and volunteers at the patient’s bedside, as well as those throughout the organization who provide the infrastructure and support for these direct patient encounters. We used to say that hospice was “high touch — not high tech,” although that phrase was never meant to suggest that hospice care providers were less than skilled. With continued advances in professional practice, the quality of hospice care depends more than ever on the caliber of the hospice workforce — its skills, training, credentials, commitment and orientation to quality.

Workforce excellence is the sixth of 10 components of the Quality Partners initiative and reflects NHPCO’s commitment to ensuring that all hospice disciplines and professionals have the skills they need to meet the needs of patients and families. This commitment to professional advancement for the hospice workforce can be illustrated by the example of physicians and nurses, although advancement is also reflected in the other disciplines on the hospice interdisciplinary team.

The practice of hospice and palliative medicine took a huge step forward last September when the American Board of Medical Specialties recognized it as a legitimate medical subspecialty. Along with recent standards development by the American College of Graduate Medical Education and growing numbers of palliative medicine fellowships nationwide, this formal recognition of hospice and palliative medicine mainstreams a process that began in 1995 with the formation of the American Board of Hospice and Palliative Medicine (ABHPM).

ABMS recognition “is a watershed event for our field, and a precedent-setting example of collaboration between 10 medical specialty boards,” says ABHPM executive director Dale Lupu. Starting in 2008, certification exams will be given by the 10 boards under ABMS, while ABHPM will be phased out. By 2013, new physicians entering this field will need to complete a formal medical fellowship in palliative medicine, not just have experience working in the field, which means that a lot more fellowship slots must be created. “We are working to develop fellowship opportunities that are friendlier to physicians in mid-career,” Lupu says.

Not counting those who sat for the recent exam in November, there are 2,142 U.S. physicians board-certified in hospice and palliative medicine, not enough to cover every hospice in America. However, hospice administrators can encourage their current medical directors to study and seek board certification while identifying physicians in the community with an aptitude and interest in end-of-life care and recruiting them as associate or volunteer medical directors. Since physicians who want to sit for their boards in hospice and palliative care medicine must have experience working with an interdisciplinary team, hospices can offer them an opportunity to gain that experience on the job.

Clearly, Lupu says, the more successful hospices tend to have strong physician leadership. For administrators, pushing their medical directors toward board certification, networking with peers, and attendance at hospice conferences is an obvious way to enhance their medical skills and raise the quality of the team as a whole.

All Members of the Nursing Team
Hospice nursing has also been advancing its professional practice through certification since 1993, when the National Board for Certification of Hospice and Palliative Nurses (NBCHPN) began offering a professional exam for certified hospice
and palliative nurses. Developing a certification process is a time- and resource-intensive endeavor, building on an extensive role-delineation survey, says Judy Lentz, executive director of NBCHPN and CEO of the Hospice and Palliative Nurses Association. Today there are 9,217 certified hospice and palliative nurses, while subsequent exams have been added for nursing assistants (starting in 2002, with 3,325 certified), advanced practice nurses (2003, 317 certified), and licensed practical/vocational nurses (2005, 754 certified).

“We believe the entire nursing team in hospice should be certified in every hospice and palliative care setting,” Lentz says. However, certification has not reached the level of saturation nationally that would make this possible for most providers. “Many hospices have told us they are striving to achieve 100 percent, and NHPCO’s Quality Partners is going to help encourage additional progress in this area.”

There are a number of things that other hospices can do to encourage professional credentialing by their nursing staff. They can give paid time off for nurses sitting for the exam, offer increased pay for those who earn this credential, and hold a celebration or other form of recognition for those who pass. “We find it helpful to encourage people to study together and take the exam together,” Lentz says. “But when the employer does not support this process, then it’s harder to convince the employee of its merit.”

Other examples of an organizational commitment to workforce excellence in hospice care can be found in NHPCO’s Standards or on the Quality Partners Web site (nhpco.org/quality). They include:

- Treating volunteers as a critical segment of the hospice workforce;
- Keeping channels of communication open for employees to freely express their concerns;
- Establishing and observing staff-to-patient ratios sufficient to meet patients’ needs;
- Offering emotional support to hospice team members through the bereavement coordinator and/or access to employee assistance programs;
- Providing education for administrators and governing body members;
- Preserving a supportive and mutually respectful working environment that reflects cooperation and coordination among team members.

A variety of quality resources and tools can be found at nhpco.org/quality. NHPCO has also developed guidelines for nursing in hospice care and for spiritual care professionals, among others. For more information on physician credentialing, visit the Web sites of the American Academy of Hospice and Palliative Medicine (aahpm.org) and the American Board of Medical Specialties (abms.org). For information on nursing certification, call NBCHPM and HPNA at 412/787-9301 or visit hpna.org.

— Larry Beresford

For an update from one of the participants in NHPCO’s Clinical Excellence Collaborative, see page 54.
Stat of the Month:
Hospice Staff Turnover Rates

Findings from NHPCO’s annual online survey, the National Data Set (NDS), shed light on important trends in the growth, delivery, and quality of hospice and palliative care across the country. This month, we spotlight NDS findings as they relate to staff turnover.

Results from the 2005 survey show the turnover rate for clinical staff (providing direct patient care) was 24.1 percent, while the rate for all staff was 25.3 percent. The chart at right provides a closer look at turnover rates by discipline.

Staff turnover is an important element in the provision of quality care, significantly impacting continuity of care and workload demands for remaining staff as well as staff training expenses. Even the implementation of quality improvement programs and interventions can be negatively affected by staff turnover.

For a closer look at NDS findings, visit nhpco.org/nds.

The NHF Board of Trustees is pleased to present the

2007 National Hospice Foundation Gala
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For more information please contact
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klucas@nationalhospicefoundation.org
www.nationalhospicefoundation.org
Does your hospice or coalition need Spanish language brochures or ones that address pediatric issues? Check out these newest resources from Caring Connections:

**Spanish Language**
- End-of-Life Decisions: Clinical Issues
- End-of-Life Issues: Advance Directives
- Planning for Long Term Care
- Coping with Loss
- Hospice Care
- Palliative Care

**Pediatric (also available in Spanish)**
- Talking with Your Children About Their Illness
- When Your Child is in Pain
- When a Child Dies: A Guide for Family and Friends
- Talking to Your Child’s Doctor: When Your Child has a Serious Illness

**Workplace Specific**
- When a Co-Worker Dies
- When an Employee Dies

**End-of-Life Decision Making**
- End-of-Life Decisions: Clinical Issues
- Planning for Long Term Care
- End-of-Life Financial Issues

**Grief and Loss**
- Coping with Loss
- Supporting Someone Who is Grieving

**Caregiving**
- How to Support Someone Caring for Another

**Where to Find Them:**
Individual copies can be downloaded from the Caring Connections Web site (caringinfo.org), free of charge. They can also be purchased in bulk from NHPCO’s Marketplace: call 800/646-6460 or visit nhpc.org/marketplace (under Product Type, select “Caring Connections Brochures”).

Also planned for release in 2007 are brochures on: How to Manage Your Pain; Spiritual Care at the End of Life; Understanding the Dying Process; and Funeral and Memorial Planning. Look for announcements in future issues of NewsLine and NHPCO’s weekly e-newletter, NewsBriefs.
People and Places

5191 Care Fund Provides for Bereavement Support
After the tragic crash of Comair Flight 5191 in Lexington, KY last August, community members responded with an outpouring of financial support for the victims’ families. At the request of the community, the United Way of the Bluegrass established the 5191 Care Fund (uwbg.org) to provide assistance to the passengers’ families. So far, more than $60,000 has been contributed to the Fund.

Lexington’s Hospice of the Bluegrass was designated as a partner in the program and is charged with helping family members get bereavement support and counseling, as well as other ongoing services to help them deal with their grief. For more about the program’s efforts, see page 32 of Robin Fiorelli’s article, Filling a Need for a Grieving Public.

Haven Hospice Transitions Program Receives Healthcare and Aging Award
The Transitions Program of Haven Hospice (Gainsville, FL) was awarded the 2007 Healthcare and Aging Award by the Healthcare and Aging Network and the American Society on Aging, in collaboration with Pfizer Inc. The Healthcare and Aging Award is given to organizations that have demonstrated high-quality, innovative programs that enhance quality of life for older adults. Haven Hospice’s Transitions Program provides comprehensive outreach support and education to individuals and families who are dealing with serious illness. It strives to be more than a “traditional” support group, offering presentations, printed materials, and a focus on education about living with a life-limiting illness.

Chamber of Commerce Names Nonprofit of the Year
Hospice of Central Ohio (Newark) received the Licking County Chamber of Commerce’s Award for Nonprofit of the Year. This recognition reflects on the many hours of dedicated service the hospice’s staff and volunteers provide to families in the community. Michele McMahon, president/CEO, accepted the award at a ceremony this past August. She thanked staff and volunteers for not only providing many hands, but also many hearts to patients, families, and their special friends throughout the past 24 years.

Hospice Staff Becomes Certified in Hospice Care
All of the clinical staff from Hospice of Northeastern Illinois who recently took the National Hospice Certification exam successfully passed, giving the agency a 100 percent pass rate. Although not a requirement for hospice CNAs and nurses, it is strongly encouraged by the agency. Successful completion of the exam helps demonstrate both agency and staff commitment to maintaining a high level of expertise in the field.

Agency staff who passed the Certified Hospice and Palliative Nursing exam include: Helen Alums, RN; Regina Dix, RN; Kristen Drago, RN; Pam Gertig, RN; Sue Griffin, RN; Ann Landmark, RN; Molly Montrie, RN; and Mardi Wiedelman, RN. Those who passed the Certified Hospice and Palliative Nursing Assistant exam include: Lisa Dunham, CNA; Socorro Ramirez, CNA; Michelle Rayphole, CNA; and Sheila Thorton, CNA.
In Memoriam...

Pulitzer Prize winning journalist and hospice advocate, Art Buchwald, died on January 17 at his home in Washington, DC. He was 81. Over the course of the past year, Mr. Buchwald has written poignantly about his battle with kidney disease, the choices he made to focus on quality of life, and the wonderful care he received from the Washington Home and Hospice in Washington, DC.

In his radio and television interviews, and in his syndicated news columns (which NHPCO frequently shared via the weekly e-newsletter, NewsBriefs), Mr. Buchwald described the months he spent with hospice as the time of his life. “Art found unexpected joy and richness in the final phase of his life,” said NHPCO’s president/CEO, Don Schumacher. “Through his humor and openness to share his personal experiences, Art did so much to educate the public about hospice and finding a good death on one’s own terms. We thank him for the special lessons he taught us.”

Mr. Buchwald repeatedly acknowledged the support of hospice as key to the happiness he found at a time he never expected. At the National Hospice Foundation Gala in April 2006, NHPCO honored him with the Hospice Champion Award, which his son, Joel, and daughter-in-law, Tamara, accepted on his behalf (shown in the picture at right). They were at his side when he died.

NHPCO honors Mr. Buchwald and extends its sympathies to his family and friends.
What’s Been Happening at Midwest

The Quality Improvement Clinical Collaborative (NewsLine, 12/06), launched this past September as part of the Quality Partners program, brought together 13 hospice and palliative care organizations for a nine-month quality improvement project.

Collaborative participant, Midwest Palliative & Hospice CareCenter, based in the Chicago suburb of Glenview, chose to focus on caregiver confidence at the end of the patient’s life. When family caregivers were surveyed at the start of the collaborative, just 50 percent felt they were “very confident” about what to expect when their loved one was dying. The CareCenter’s goal was to raise that to 75 percent by the end of the collaborative in April.

Toward this end, the program’s Violet Team, which provides care in northwest Chicago, has been asking all patients and families specific questions about their confidence level, what they are expecting to happen, and how staff can help them. Collaborative team members are also calling families to inquire about their confidence levels following the death of the patient. Results from these interventions will be measured against a control group to determine if these actions have been effective.

“In addition to learning about quality improvement how to’s, and working to improve caregiver confidence levels, collaborative team members are helping to create a ‘culture of quality’ within the organization,” said Julie Bruno, LCSW, the program’s senior clinical director. “We’ve made a concerted effort to keep all members of the organization up to speed on the project and make sure everyone feels they have a voice in what’s being done.”

Results from CareCenter’s work, along with feedback from other collaborative participants, will be available to members once this first Clinical Collaborative concludes in April. Look for updates at nhpco.org/quality.
As part of Quality Partners, NHPCO’s Marketplace is featuring resources germane to the 10 components of quality. This month, we spotlight materials related to Workforce Excellence.

**Dates to Remember**

**NHPCO’s Audio Web Seminars**

**Interdisciplinary Topics** – second Thursday of the Month, 2:00 – 3:30 pm ET.

- 04/12/07 — Effective Pain Management with Methadone: Challenges and Opportunities
- 05/10/07 — End-Stage Renal Disease: When Is It Time for Hospice?

**Leadership Topics** – fourth Tuesday of the Month, 2:00 – 3:30 pm ET.

- 04/26/07 — Ensuring Workforce Excellence: Recruitment, Retention, Recognition
- 05/22/07 — Understanding, Utilizing and Managing Change in Your Organization

**NHPCO Conferences**

- April 19 – 21, 2007 — 22nd Management and Leadership Conference, Washington, DC
- July 30 – August 1, 2007 — Caring For the Mind, Body and Spirit: Psychosocial, Bereavement, and Spiritual Needs, Albuquerque, NM
- November 29 – December 1, 2007 — 8th Clinical Team Conference, New Orleans, LA

**Hospice MDP Two-Day Foundational Course**

- April 17-18, 2007 — Washington, DC
- July 28-29, 2007 — Albuquerque, NM
- November 27 – 28, 2007 — New Orleans, LA

Additional MDP Level I and II modules are available in online formats! Visit nhpco.org/mdp for more information.

April 18, 2007 — National Hospice Gala,

**Marketplace Picks**

The Nurse Manager’s Survival Guide
By T. M. Marrelli and Lynda S. Hillard
Item: 820605, Member: $32.33

What Do I Say?
By Rita Layson, MD, MSW, and Debbie Garner, MSW
Item: 820384, Member: $229.00

The Educated Caregiver
3 DVD Set
Item: 715137, Member: $64.99

Grief in the Workplace Kit
Packet of 8 brochures
Item: 821010, Member: $6.50

Advice for Healthcare Providers: Care for Dying Patients
Item: 820648, Member: $0.78

Home Health Care...
When Home is Where you Want to Be
Video, 12 minutes
Item: 82095, Member: $29.99

To order, visit nhpco.org/marketplace or call 800/646-6460. Mention Code: NL03
Please visit our Web site at nhpco.org.

Candle of Hope won first place under the “Child” category in NHPCO’s 2006 Photo Contest. Taken by Greg Campbell from Baptist Trinity Center for Good Grief in Memphis, Tennessee, it’s yet another example of the high-quality work the contest draws each year.