Vision
A world where individuals and families facing serious illness, death, and grief will experience the best that humankind can offer.

Mission
To lead and mobilize social change for improved care at the end of life.

Values
NHPCO believes in:
Service... engaging customers;
Respect... honoring others;
Excellence... exceeding expectations;
Collaboration... fostering partnerships;
Stewardship... managing resources.

NHPCO extends its deepest appreciation to the many members who provided the photographs seen throughout this report.
To every member who has helped share the story of hospice and palliative care in these pages—thank you!
As I enter my eighth year as president/CEO of NHPCO, I am astounded at how our field has changed. Most notably, more and more people are receiving the benefits of hospice and palliative care—and the growth in providers is heartening. The difficult news is that the kind of growth we have experienced is not entirely understood by some of the policy makers and regulators who are struggling with the increasing costs of healthcare and have just begun the work of implementing the new healthcare reform law.

Hospice staff and leaders have always been mission-driven on the road toward our success. While the journey has never been smooth, it has always felt like we were fighting the good fight together. That fight has become more and more complicated and may become increasingly so in the future. There will be regulatory challenges as we face increased scrutiny. We must continue to protect hospice reimbursement while we examine different reimbursement models. The hospice and palliative care community must stand together and speak with one voice as we cope with realities of an expanding field.

As I look toward our future, I am thankful for many things: strong board leadership; a talented senior team; dedicated staff members who appreciate the importance of their work and excel at it; many providers who are actively engaged with the work we are doing together; and the knowledge that we will survive the current pressures and continue to thrive.

This report briefly summarizes some of NHPCO’s achievements from the past year, achievements that would not be possible without the continued support and participation of our members and supporters. For the increasingly vital role that you play, thank you.

J. Donald Schumacher, PsyD  
President and CEO
Hospice and palliative care offer individuals living with a serious, life-limiting illness or condition expert pain and symptom management combined with holistic care and support. This enables patients and their family members to focus on living rather than dying.

While diverse in structure, hospice and palliative care providers are unified in their mission. Americans are fortunate to enjoy the services of a wide range of providers—from small all-volunteer agencies that care for fewer than 50 patients per year to large, national programs that care for thousands of patients each day.

NHPCO closely monitors trends among hospice and palliative care programs and serves as the trusted source of information to providers, regulators, legislators, media, and consumers. The following facts provide a snapshot of hospice care in the U.S.

**How many people receive care each year?**
An estimated 1.45 million patients receive care every year; 38.5 percent of all deaths in the U.S. were under the care of a hospice program.

**How many hospice programs are there?**
There are approximately 4,850 hospice providers nationwide.

**How long do most patients receive care?**
The average number of days—or average length of service—that a patient received care rose to 69.5 days in 2008. Thirty-five percent of hospice patients died or were discharged in seven days or less, and twelve percent died or were discharged in 180 days or more.

**Where is care provided?**
Most hospice care is provided in the home. In 2008, 68.8 percent of care was provided in the patient’s place of residence, while 21 percent was provided in a hospice inpatient facility and 10.1 percent was provided in an acute care hospital.

**Who are hospices caring for?**
Hospice programs care for people with a broad range of diagnoses. In 2008, the top five diagnoses were:
- Cancer . . . . . . . . . . . . . . . . . . 38.3%
- Debility . . . . . . . . . . . . . . . . . . 15.3%
- Heart Disease . . . . . . . . . . . . . . 11.7%
- Dementia . . . . . . . . . . . . . . . . . 11.1%
- Lung Disease . . . . . . . . . . . . . . 7.9%

**Do patients live longer under hospice care?**
Hospice care may prolong the lives of some patients. Research has shown that patients who chose hospice care lived an average of 29 days longer than similar patients who did not choose hospice.

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**Profile of Hospice Providers**

**Total Patient Admissions**
- 1-49 admissions per year . . . . 18.1%
- 50–150 . . . . . . . . . . . . . . . . . . 29.5%
- 151–500 . . . . . . . . . . . . . . . . . . 32.1%
- 501–1,500 . . . . . . . . . . . . . . . . . 16.1%
- > 1,500 . . . . . . . . . . . . . . . . . . 4.2%

**Average Daily Census**
- 1–25 patients per day . . . . . . . . 39.3%
- 26–100 . . . . . . . . . . . . . . . . . . 40.5%
- > 100 . . . . . . . . . . . . . . . . . . . . 20.1%

**Agency Type**
- Freestanding/Independent . . . 58.3%
- Hospital Based . . . . . . . . . . . . 20.8%
- Home Health Based . . . . . . . . 19.7%
- Nursing Home Based . . . . . . 1.3%

**Organizational Tax Status**
- Not-for-profit . . . . . . . . . . . . . 49.6%
- Proprietary . . . . . . . . . . . . . . . 46.2%
- Government . . . . . . . . . . . . . . . 4.2%

A Look at NHPCO’s Membership

- NHPCO maintains a 90 percent member retention rate—higher than the average rate for professional associations.
- NHPCO represents more than 80 percent of the nation’s hospice providers.
- NHPCO provider members care for an estimated 80 percent of patients receiving hospice services in the U.S.

Organizational Members:

Provider Members ........................................... 3,792
Organizations providing hospice and/or palliative care services

Associate, Affiliate, and Allied Members ...................... 426
Companies that provide products and services, other agencies and foundations

State Organizations, including NHPCO Council of States .......... 50
Organizations working to support members within their states

Individual Members:

NHPCO’s National Council of Hospice and Palliative Professionals . . . 44,280
Individuals working for both member and non-member organizations

Total Membership .................................................. 48,548
Strategic Leadership

The following accomplishments represent NHPCO’s ongoing work to improve care at the end of life.

Enhance Quality

Every patient and family served by hospice and palliative care providers deserves the best that humankind can offer.

- Revised the NHPCO Standards of Practice for Hospice Care to reflect historic changes in federal regulations. The supplemental “Crosswalk” comparing the Standards with the CoPs, JCAHO, CHAP and ACHC, was also revised.
- Continued work with CMS, MedPAC, OIG, FDA, and other federal agencies on issues affecting the quality and delivery of care.
- Developed position statements on access to palliative care in critical care settings and palliative sedation therapy.
- Contributed measures from the Family Evaluation of Hospice Care and End Result Outcome Measures to the Agency for Healthcare Quality and Research for inclusion in its National Medical Quality Clearinghouse (the only end-of-life care data that met the federal agency’s high standards for inclusion).
- Expanded the Hospice Volunteer Program Resource Manual to help providers develop and enrich volunteer programs.
- Developed Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings in conjunction with the nation’s state and federal prison systems and state hospice organizations.
- Continued to refine the Quality Partners Self Assessment System (www.nhpco.org/quality) that is utilized by more than 650 providers to help identify and prioritize areas for improvement.

Engage Partners

Because the needs are too great to undertake alone, NHPCO works collaboratively with a diverse range of interested stakeholders.

- Collaborated with state organizations, through NHPCO’s Council of States, to ensure that state and national initiatives support one another.
- Participated in a national advisory council in partnership with Easter Seals to improve collaboration between adult day service providers and hospices.
- Worked with the National Rural Health Association, PACE and others to address concerns in rural settings.
- Offered an Education in Palliative and End-of-life Care training module at the NHPCO Clinical Team Conference.
Increase Access

While awareness of hospice has increased, there are still too many people who learn about their care options too late, if at all:

- Advocated for improved access to hospice and end-of-life care in both the House and Senate healthcare reform proposals.
- Published NHPCO’s first national Standards of Practice for Pediatric Palliative Care and Hospice and the report, Facts and Figures: Pediatric Palliative and Hospice Care in America, to help focus attention on children’s unmet needs.
- Awarded 18 “Reaching Out” grants on behalf of the Department of Veterans Affairs with the goal of helping the VA support veterans who are homeless or living in rural areas and in need of end-of-life care.
- Developed resources to facilitate better access to hospice care among patients with chronic kidney disease.
- Published the Disability Outreach Guide, the seventh in a series of guides to help providers improve access among underserved populations.
- Disseminated new outreach materials to promote understanding of hospice, palliative care, advance care planning and related topics.

In 2009, a record number of members utilized NHPCO’s survey tools to help assess the quality of their services. Here’s a glimpse of the numbers:

**Family Evaluation of Hospice Care**
Over 1,300 providers submitted data on nearly 220,000 patients/caregivers.

**Family Evaluation of Bereavement Services**
Over 400 providers submitted data on 3,400 bereavement clients.

**End-Result Outcome Measures**
Data on nearly 45,000 patients were received.

To learn more visit [www.nhpco.org/research](http://www.nhpco.org/research).

- Developed an advanced certification program for social workers, in collaboration with the National Association of Social Workers.
- Served as a founding member of the National Collaborative for Pediatric Palliative and Hospice Medicine.
- Sponsored training in collaboration with the Mid Atlantic Renal Coalition and Kidney End-of-Life Coalition to increase access to hospice.
- Participated in the Institute of Medicine’s meeting, Breaking the Mold: New Options to Enhance Care and Empower Patients.
- Provided leadership for National Healthcare Decisions Day in collaboration with 800 national, state and local organizations.
- Participated in the monthly meetings of the Hospice and Palliative Care Coalition—with AAHPM, CAPC, HPNA and NPCRC—to strategize on issues of common concern.
- Licensed Caring Connections consumer resources to hospitals, faith communities, health plans, senior service providers and others.
Support Providers

Providing hospice and palliative care professionals and organizations with the resources they need to sustain and improve their work will ultimately benefit the patients and families who need care.

- Led efforts along with The Alliance for Care at the End of Life that achieved a one-year moratorium on the elimination of the Budget Neutrality Adjustment Factor (BNAF) and brought $136 million back to the hospice community in 2009.
- Secured a seven-year phase-in of the BNAF’s elimination, rather than the proposed three-year period, enabling the hospice community to plan for and absorb the $2.9 billion loss over a longer term.
- Provided analysis of legislative proposals and bills affecting end-of-life care, keeping providers and advocates informed and involved.
- Monitored proposed and changing federal regulations on a daily basis and provided analysis to the field.
- Developed a range of resources, exclusively for members, to assist with the many regulatory changes, including a Wage Index calculator, physician certification/recertification sample forms, and tip sheets to assist with ADRs, probe-edits and care for patients across state lines.
- Provided direct regulatory assistance in response to over 5,000 member inquiries.
- Hosted three national conferences including the 6th National Conference on Volunteering and Family Caregiving.
- Increased access to web-based education by expanding offerings available through NHPCO’s End-of-Life Online (E-OL) and the Hospice Manager Development Program.
- Introduced the EDGE distance learning portal, featuring reduced registration rates, online CEs, and MP3 download availability.
- Reached 38,000 professionals via NHPCO Webinars and offered Webcasts of national conference plenary sessions.
- Updated the Guidelines for Spiritual Care in Hospice.
- Offered an expanded online Hospice Career Center with thousands of professional opportunities.
- Added 100 new products to NHPCO’s online retail store, Marketplace, and featured a range of Marketplace items at state and industry-related conferences.

Advance Data/Research

As regulators, policy makers, payors and consumers demand more accountability and return on investment, data collection and reporting as well as research are vitally important to the future of hospice and palliative care.

- Contracted with The Moran Company to review MedPAC recommendations for hospice payment reform, gather data from the hospice community, and analyze various reimbursement models.
- Appointed a Data Advisory Council to advise The Moran Company on payment reform models.
- Published the National STAR Report, an annual report summarizing results from NHPCO’s Survey of Team Attitudes and Relationships.
- Conducted an Economic Impact Survey to help assess the impact and expected ramifications of the economic downturn on providers.
- Sponsored a literature review of hospice care in the nursing home.
- Continued collaboration with Brown University’s Center for Gerontology and Health Care Research on a project examining late hospice referrals.

Caring Connections and Google Health™ teamed up to increase online availability and access to advance care planning information.

Through their collaboration, consumers can establish a secure account on Google Health making their advance directives accessible in an emergency.

Visit the Caring Connections website (www.caringinfo.org) for instructions and a quick link to Google Health.
Empower Consumers

More individuals and families must learn how to ask for hospice, palliative care, grief support, caregiving resources and advance directives.

- Distributed four televised public service announcements that reached more than 880,000 viewers nationwide, representing over $630,000 of airtime.
- Created six informational videos for the Internet explaining the basics of hospice care.
- Launched an 18-month project under Caring Connections to increase awareness about the needs of family caregivers in the workplace.
- Developed four online, self-learning modules to support the role and work of family caregivers.
- Commissioned The Legal Guide for the Seriously Ill from the American Bar Association.
- Was highlighted as a recommended resource in leading media outlets, including The Oprah Magazine, 60 Minutes, New York Times, and National Public Radio stations across the country.

Inspire Advocates

Faced with budget cuts and healthcare reform, NHPCO’s leadership of national efforts to advocate on behalf of end-of-life care is more important than ever.

- Registered 60,000 individuals as Hospice Advocates as part of the Hospice Action Network (www.nhpco.org/advocacy).
- Coordinated visits of 600 Hospice Advocates with members of Congress and staff during NHPCO’s annual Capitol Hill Day.
- Crafted a letter to President Obama on behalf of the hospice and palliative care community that included the names of 3,524 programs that lent their support.
- Issued a call to action that led to 100,000 calls, emails, and letters sent to Congress and the White House from hospice staff and volunteers, community members, and patients and families.
- Reached 1.19 million listeners over 548 radio stations with a radio tour featuring President/CEO Don Schumacher.
- Launched the “Two Cuts are Too Much” campaign, targeting both Congress and the media in response to proposed cuts to offset the future cost of healthcare reform.
- Placed ads in key Washington publications and venues to amplify key messages.
- Created the Advocacy Action Pledge Kit to help Hospice Advocates engage their representatives.
- Expanded outreach using social media that included personal video testimonials.
One of the most significant accomplishments in the past year has been the release of NHPCO’s new strategic plan—a roadmap that includes some very specific objectives and initiatives that will help NHPCO address many of the concerns relevant to the field.

The new plan “builds upon” the Blueprint for Quality and Access, NHPCO’s first, formal leadership-focused strategic plan that was adopted in 2005. In fact, the National Center for Care at the End of Life—our new home at 1731 King Street—served as the visual inspiration for the plan’s strategic framework.

The four pillars represent what will be the areas of primary focus over the next three years: Leadership, Quality, Access, and Innovation, while the building’s other structural elements represent the strategic and infrastructure areas integral to achieving our vision and mission.

The development of this plan was greatly enriched by the input of a diverse cross-section of members and professionals from a range of programs and organizations around the country and NHPCO extends its gratitude to all those who contributed to this important work.

Visit the NHPCO website to read the digital version of the strategic plan (www.nhpco.org/mission).
Opening Doors to Greater Collaboration

November 2009 marked NHPCO’s first anniversary at its new headquarters in the National Center for Care at the End of Life. There were a number of financial and logistical benefits that made our relocation to the National Center a very good move. Among them was far more functional workspace, including several large meeting rooms that eliminated the need to rent space for NHPCO’s all-team meetings and other gatherings.

While moving to the National Center has provided a clear cost benefit, it has also, quite literally, given us the room to expand our collaborative work. We have been able to host meetings to support association partners, external stakeholders, and the community that would have been impossible to do in our former office space.

Over the past year, we held the first face-to-face meeting of our new Data Advisory Council; hosted a Town Hall Meeting during initial discussions about healthcare reform; led a two-day orientation for new and returning members of NHPCO’s Council of States; held an Industry Roundtable with national corrections leaders to support their development of hospice services in correctional medical facilities; and welcomed community members for educational programs, which included several events that shared the work of our affiliated organizations.

The value of establishing a National Center is now quite clear. The next step is the National Hospice Foundation’s launch of a capital campaign that will fund the purchase of our new home. Details on this new initiative will be shared with members in the coming months.
NHPCO Financial Statements
Year Ending December 31, 2008

ASSETS

Assets
Cash and cash equivalents $ 761,299
Investments 2,849,334
Accounts receivable, net 559,641
Grants receivable 347,780
Inventory, net 1,480,578
Prepaid expenses and other assets 409,248
Property and equipment, net 1,758,368

Total Assets $ 8,166,248

LIABILITIES AND NET ASSETS

Liabilities
Accounts payable and accrued expenses $ 1,061,268
Due to Affiliates 4,715
Grants payable 848,736
Line of credit 950,000
Deferred revenue 658,234
Deferred rent 893,754

Total Liabilities $ 4,416,707

Net Assets
Unrestricted $ 2,557,047
Temporarily restricted 1,192,494

Total Net Assets 3,749,541

Total Liabilities and Net Assets $ 8,166,248
Statement of Activities 2008

**REVENUE**

Membership dues $ 5,388,334  
Grants and contributions 962,213  
Conferences and symposia 2,700,858  
Publications and products 1,330,198  
In-kind donations 284,301  
Licensing 144,390  
Management fees 1,403,057  
Royalties 65,621  
Other income 111,900  

Total Revenue and Support $ 12,390,872

**EXPENSES**

*Program Services:*

Consumer and caregiver services $ 1,535,786  
Clinical excellence, quality and research 1,303,367  
Communications 458,145  
Financial resources & fundraising 2,164,099  
International development 261,040  
Public policy and advocacy 1,169,877  
Provider support and access 3,474,861  

Total Program Services $ 10,367,175

*Supporting Services:*

Administrative and general $ 3,646,507  
Total Expenses $ 14,013,682  
Change in net assets from continuing operations $(1,622,810)  
Investment income $(489,930)  

Change in Net Assets $(2,112,740)

**NET ASSETS**

Beginning of Year $ 5,862,281  
End of Year $ 3,749,541
NHF Donors Fueled Key NHPCO Programs with $275,000

In 2009, the National Hospice Foundation transferred $275,000 to NHPCO to enhance our ability to achieve strategic goals. This significant contribution represents gifts from donors in the form of annual fund gifts, memorial contributions, proceeds from the NHF gala, and other non-designated donations to NHF.

This unrestricted support was applied by NHPCO to support key projects that are not fully covered by membership dues. These projects are all of crucial value to NHPCO’s mission—and NHPCO’s accomplishments would not be as robust without the generosity of NHF donors.

With NHF funding in 2009, NHPCO accomplished the following:

- Reached hundreds of thousands of families and caregivers through the resources of Caring Connections, including the comprehensive website (www.caringinfo.org), the HelpLine (800-658-8898), and educational materials.
- Provided cutting-edge education to hospice professionals through the development of new online courses.
- Helped build nationwide awareness of hospice through the creation and dissemination of outreach campaign materials.
- Improved the quality of hospice care through analysis of performance measurement data supplied by NHPCO members.
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Hospice of the Bluegrass
Lexington, KY

President and CEO
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NHPCO
Alexandria, VA

Samira Beckwith
Hope HealthCare Services
Ft. Myers, FL

Tara Brodbeck
Hospice of the Miami Valley
Xenia, OH

Kavin Cartmell
Hospice of Hope
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Elizabeth Clark
National Association of Social Workers
Washington, DC

Kate Cummings
Fairview Home Care and Hospice
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Durham VA Medical Center
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NHPCO Affiliate Organizations

National Hospice Foundation

Envisions a world where everyone facing serious illness, death, and grief will experience the best that humankind can offer. This is the vision shared by our family of affiliated organizations. To make this vision a reality, NHF supports NHPCO’s quality and research initiatives; hospice/palliative care provider education activities; consumer engagement and caregiver services; and the FHSSA Impact Fund. Learn more at www.nationalhospicefoundation.org.

FHSSA

Founded in 1999 as the Foundation for Hospices in Sub-Saharan Africa, FHSSA provides compassionate care where the need is great and resources are few. FHSSA connects organizations in the U.S. and sub-Saharan Africa through partnership and collaboration. FHSSA supports our partners in expansion of comprehensive care services to transform communities, families and individuals, and to sustain efforts that multiply the impact of services on the ground. Learn more at www.fhssa.org.

The Alliance for Care at the End of Life

Works collaboratively with NHPCO as a strategic lobbying entity for the hospice and palliative care community. Created in 2007, the Alliance provides a more aggressive, focused and unified voice that serves the entire field and, ultimately, one of America’s most vulnerable populations—those nearing the end of life and their families. The Alliance launched the Hospice Action Network connecting more than 60,000 individuals to efforts protecting end-of-life care. Learn more at www.afceol.org.