

# VA Transforms End-of-Life Care for Veterans



Vietnam-era veteran Stephen Pavon lived on an isolated horse ranch in Nevada until cancer forced him to move to the hospice unit at the VA Medical Center in Palo Alto, California

Stephen Pavon served in the Marine Corps Air Wing from 1963 to 1967, including a tour in Vietnam. While on active convoy duty, he was injured twice, patched up and sent back out. During the “times of turmoil” that followed his discharge, Pavon was a fireman, a college student, and a hippie in Berkeley, Calif. Later, he taught transcendental meditation, traveled the world, and worked overseas as an engineer before finally landing as a horse trainer on a ranch in Nevada.

Now Pavon, 57, is fighting another battle, one he will not win, against rectal cancer. He will spend his final days at the Veterans Affairs Palo Alto Health Care System in Palo Alto, Calif., where Dr. James Hallenbeck, Director of Palo Alto’s Palliative Care Services, and his team are building and refining a new model of expert, compassionate, supportive care for veterans nearing the end of their lives.

“I’ve never heard a ‘no’ here,” Pavon reports. “The support is so complete that it allows me to be comfortable and to live my final days in comfort. I get to personalize my room. I can still maintain control of my heart, my mind, and my intelligence.”

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## Editor’s Note:

*This report portrays advances in end-of-life care for veterans by the Department of Veterans Affairs (VA). A joint project of VA and the National Hospice and Palliative Care Organization (NHPCO), this report describes VA hospice and palliative care benefits, the needs of terminally ill veterans, and the role of partnering community hospice programs. It features stories of individual veterans and their families who have benefited from that care.*

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# A Message from The Honorable Anthony J. Principi Secretary, United States Department of Veterans Affairs



Our National reflection in the 'mirror of demographics' clearly shows us that the face of America is aging. And with it, the face of America's veterans. The generations of men and women who forged the American Century are now living out their golden years, many with memories of their military service in World War II ... Korea ... the Cold War ... and for some, even Vietnam. The battles they fought with guns and grenades have faded into the fog of history ... but the battles they now fight against the physical and mental challenges of aging demand a range of services and interventions.

The magnitude of the issues presented by aging veterans is underscored by the sheer weight of their numbers. Of all Americans who pass away this year, more than one-quarter will be veterans of our Nation's armed services. Nearly 1,600 veterans die every day, and in this year alone, more of them will die than did during all four years of the Second World War.

Our country's veterans shoulder a proud heritage of service and sacrifice in both war and peace ... at home and abroad. America's covenant with them – from her most elderly veteran of the War to End All Wars ... to

her youngest hero of the war on terrorism – is drawn from President Abraham Lincoln's noble Civil War promise "to care for him who shall have borne the battle ...."

The power of Lincoln's pledge rests with the Department of Veterans Affairs and its determination to do the very best it can for those who once did their very best for us. As steward of the Cabinet Department that is their National Advocate, I personally am committed to upholding Lincoln's pledge to veterans, as well as the promises of the presidents and Congresses that followed.

VA's palliative and end-of-life care offers an opportunity to provide veterans a peaceful journey across life's last years, as well as an opportunity to provide them the respect and recognition they so well deserve through dignified, quality care. Ours, then, is a final chance to fulfill a last promise.

Because VA is the largest integrated health care system in the country, we are well positioned to be a National leader in this highly specialized area of care. We have called attention to the need for a coordinated, collaborative approach that not only addresses, but publicizes the many emerging developments in end-of-life care among our employees, our customers and their families, and our many partners in the health care community. VA's Office of Geriatrics and Extended Care is fully engaged in weaving the complement of hospice and palliative care options into the fabric of our wide-ranging health care services.

Our mandate is to honor each and every veteran's preference for end-of-life care, and we have made a clear, consistent, and permanent commitment to achieving that goal. For example:

- Hospice and palliative care is now a covered benefit for all enrolled veterans.
- By policy, we have hospice and palliative care consult teams and/or inpatient units at every VA health care facility.
- As standard practice, VA now purchases comprehensive hospice services from the local communities it serves.
- Management personnel are institutionalizing hospice and palliative care within our operations, VA-wide. And because care and education go hand-in-hand, ongoing training is creating an enduring network of VA clinicians, educators, and administrators skilled in this burgeoning field of health care.
- As of this fiscal year, VA includes home hospice care in our annual budget submitted to Congress.
- Our Hospice-Veteran Partnership initiative with state and national organizations strengthens VA alliances with our community partners to improve access to end-of-life care. While VA does not directly provide comprehensive home hospice services, it is critical for us to build solid working relationships with the hospice community in order to provide these services to veterans under our care. VA has established partnerships in a growing number of states and we anticipate cementing partnerships with all states by the end of Fiscal Year 2005.

There comes a time when all the cutting-edge medicine in the world can't cure the illness, treat the disease, or slow the aging process. It is at that point, when our hospice and palliative care services stand as our last opportunity to thank America's veterans, to provide them comfort and compassion, and to help them find peace in the final days of their lives.

The comprehensive hospice programs we encourage and the skilled palliative services we offer, together, stand among the most personally gratifying achievements in my tenure as Secretary. As the Department of Veterans Affairs continues to push back the horizons of end-of-life care and add yet another aspect to his time-honored promise to veterans, I like to think President Lincoln would be both pleased and proud.

When the 25-bed Palo Alto Hospice Care Center was created in 1979, it was at the vanguard of a national hospice movement that would transform care for dying people nationwide. Today, the Hospice Care Center remains at the forefront of innovation. It received a 2001 Citation of Honor through the American Hospital Association's Circle of Life Awards for exemplary end-of-life care. It is also the hub site for a network of six interdisciplinary hospice and palliative care fellowship training programs within the VA.

The unit's staff includes psychologists, a half-time massage therapist, and 25 volunteers, in addition to the requisite hospice doctors, nurses, social worker, and chaplain. Families, who often travel to be near a loved one, may stay overnight on roll-out beds or in free facilities on the hospital's campus, says Hallenbeck, who, in addition to his role at the hospice care center is assistant professor of medicine at nearby Stanford University.

### VA Programs Treat Body, Mind and Spirit

Hospice care, whether it is provided inpatient in VA medical centers (VAMCs) or in patients' private residences by partnering community hospice programs, combines expert symptom management and pain relief with compassionate attention to the psychological and spiritual dimensions and family dynamics that arise when confronting a terminal illness. Quality of life becomes paramount when its quantity is limited. Hospice also supports grieving family members for a year or more after the patient's death.

For the national VA health system, recent advances in developing, refining and expanding hospice and palliative care, an approach aimed at bringing hospice's holistic, comfort-oriented care philosophy to seriously ill patients earlier in their disease progression, are not mere frills. That is because an estimated 1,600 veterans die every day in this country, most of them members of the Greatest Generation who won World War II. Now in their 80s, they are nearing the end of their natural life spans. Veterans will account for 28 percent of all deaths in the United States in 2004.

Through a national network of state and local Hospice-Veteran Partnerships (see p. 8) VA is sharing what it has learned about such care with the community agencies that provide the majority of hospice care to terminally ill veterans.

Hospice-Veteran Partnerships are part of a system-wide transformation aimed at honoring veterans' preferences for care at the end of life, says Dr. Thomas Edes who is VA's chief administrator overseeing this transformation. In response to increasing and changing demands for end-of-life services, VA has issued a number of recent directives mandating hospice and palliative care.

***"We are raising expectations at the national and local levels, so that a terminally ill veteran can go to any VA facility and obtain hospice care. If needed hospice care is not forthcoming, we want them to contact us."***

**Thomas Edes, MD, VA Chief of Home and Community-Based Care**

"We now have a framework and a structure in place," Edes says. "All of the pieces are aligned. Hospice is now a covered benefit for all enrolled veterans, home hospice care is in the VA budget for the first time, and we have a national standard for purchasing hospice care from community providers. We can track hospice workload for resource allocation and planning, and we have a hospice point of contact at every VA facility. We want to elevate expectations and make it easy for veterans to access hospice and palliative care."

While the largely autonomous local VAMCs are given flexibility to address end-of-life care according to their veterans' needs, national policy and standards stipulate that each VA facility have the following resources and services:

### Hospice and Palliative Care Are VA-Covered Benefits

*Palliative care* is an interdisciplinary team-oriented approach to expert pain and symptom management and emotional and spiritual support, tailored to individual needs and wishes and aimed at enhancing comfort and quality of life for patients with serious, life-limiting and terminal illnesses. Palliative care can be a complement to conventional, disease-modifying medical therapies or it can be an alternative when such treatments are no longer effective or not desired by the patient.

*Hospice*, the most intensive form of palliative care, is provided to seriously ill patients who have less than six months to live and who have agreed to enroll in hospice services, rather than to pursue aggressive cures for their illness. Hospice focuses on comfort for both patients and loved ones, not cure. VA defines hospice and palliative care as a continuum of comfort-oriented and supportive services provided across settings, including hospital, extended care facility, outpatient clinic, and private residence.

Hospice and palliative care are covered services, authorized in VA's Medical Benefits Package, on an equal priority with any other medical service. VA medical centers (VAMCs) must provide or purchase hospice care when VA determines that an enrolled veteran needs it. VAMCs must also provide palliative care services through consultation teams that include a physician, nurse, social worker, and chaplain. Palliative care teams offer consultation throughout a medical center, assisting with planning and guidance on managing a patient's pain and other symptoms, especially when these are complex or difficult to control.

- A designated hospice contact person who is part of an integrated network for local and national communications and information dissemination;
- Provision of needed hospice services in all settings;
- Inpatient hospice beds or access to them in the community;
- An interdisciplinary palliative care consultation team;
- Assistance with referrals to community hospices in its service area; and
- Tracking of hospice and palliative care services provided to veterans in all settings.

In many cases, the local approach may include a dedicated hospice unit, such as at the Palo Alto VAMC, based in either a hospital or an extended care facility. Palliative care teams may consult on pain and symptom management for outpatient clinics as well as throughout the hospital. VA's own home-based primary care or specialized geriatric services may also be involved in developing end-of-life care programs.

"We will institutionalize, in the best sense of the word, hospice and palliative care in the largest integrated health system in the world, proactively creating an end-of-life care system while implementing permanent changes, making it an integral part of the fabric of what VA is," says palliative care consultant Diane Jones. That kind of integration has not yet happened in the private sector, she notes, even though U.S. hospices will care for 900,000 dying patients in 2004.

"We're doing a lot of things to bolster that institutionalization... a lot of program development, a lot of action. The challenge now is to create an enduring network of skilled, trained, committed professionals," Edes adds. "It's our privilege and our responsibility to ensure that veterans receive comfort, support and care as they face their final days and that they have a choice of where they receive this care. Some don't. I am concerned that in the past far too many

veterans have suffered quietly, graciously accepting far less than the services they rightly deserve."

Although much has been accomplished in the last few years (see p. 5), more must be done to consolidate and sustain the gains at every level. The VA's newly established ability to measure and track the types of end-of-life care being provided in each facility—the *workload*—is a major step forward. Changing the medical culture from top to bottom at each facility is another significant challenge. VA leaders aim to create an environment in which VAMC staff are comfortable referring patients to hospice and palliative care and bringing up death and dying as part of routine advance care planning conversations with seriously ill veterans and their families.

*"We will institutionalize, in the best sense of that word, hospice and palliative care in the largest integrated health system in the world, proactively creating an end-of-life care system while... making it an integral part of the fabric of what VA is."*

Diane Jones, VA Palliative Care Consultant

"Is there a well-functioning palliative care team at every facility, as we have mandated? Are those teams adequately trained and staffed? At this point, probably not," Edes concedes. "But we are raising expectations at the national and local levels, so that a terminally ill veteran can go to any VA facility and obtain hospice care. If needed hospice care is not forthcoming, we want them to contact us. And we now have champions working in every VA facility, so we are getting closer to our target."

Stephen Pavon says he has encountered the VA health system twice in his life, and both experiences were positive. The first time, five years ago, he was referred to a post-traumatic stress disorder (PTSD) program at the nearby Menlo Park VA outpatient clinic.

"That saved my life. The communication skills they gave me helped me clean up my life," he says. After five failed marriages and multiple job changes, "I had turned isolation into a profession."

More recently, Pavon was living on his isolated Nevada ranch where a hospice team from Barton Memorial Hospital in South Lake Tahoe, Calif., visited and cared for him. When he could no longer manage living alone, even with the help of friends, "they had a room waiting for me here on the VA hospice unit." Before entering, Pavon wrapped up his personal business, found a good home for his horse, gave away his golf clubs and conga drums, and paid all of his bills—including a prepaid cremation service.

When he came to the Palo Alto VA hospice unit, he expected to find the same level of compassionate, spiritually oriented, medically expert hospice care that he had received from Barton Hospice—and he has. Sitting in his hospice room, wearing his black cowboy hat, Pavon reflects on a restless but full life and on the cancer that has come to dominate but not define his final days.

Mellow and sanguine about his prospects, Pavon could be a spokesperson for the hospice philosophy. "The whole underlying theme here is my comfort. I'm under 24-hour care and they've got me covered. If something isn't working, they come in and fix it and I'm back on the road. Medically, they're all up to snuff. They know how to give me the tools I need and they don't stop until I'm in my comfort zone," he says.

Pavon observes, "Sometimes, you find a simple word that explains *you*. I can relate my whole current existence, my spirituality, anything, to that concept of comfort." People are born into this world

in need of comfort, he says. Sometimes, at the end, they need more help to maintain a degree of comfort, and that's where hospice comes in.

In Pavon's case, a percutaneous infusion catheter (PIC) and portable pump deliver high doses of Dilaudid, a powerful synthetic form of morphine that keeps his pain under control without sacrificing his lucidness.

"I've had great adventures. Sometimes I wish I'd stayed a fireman—a nice, steady job," Pavon says. "But I traveled all over the world. I was always trying to fit in—trying to find where I belonged."

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Another celebrated VA hospice unit opened almost a decade ago at the Bay Pines VAMC in St. Petersburg, Fla. Clinical coordinator Deborah Grassman, a nurse practitioner, is an impassioned advocate for understanding and meeting the unique needs of combat veterans and their families (see p. 6). The 10-bed unit dispenses human kindness to facilitate opportunities for terminally ill veterans on the unit to *die healed*, in comfort and at peace. For example, the hospice unit does not restrict visiting hours—or even types of visitors, who often include young children or family pets. The unit gives families a toll-free number they can call for medical updates. Visiting children may play in a children's room whenever a break is needed for the patient or child. Disabled vets may explore the hospital grounds using motorized wheelchairs. A whirlpool bubble bath with hydraulic lift and the staff's use of healing touch modalities also enhance patients' quality of life. Hospice gives each family a "Comfort Cart" laden with aromatherapy supplies, massage oils, recorded music, and other aids for making the environment seem less institutional.

The hospice team holds weekly "quality-of-life" meetings with patients, family members and staff to discuss how to keep patients and families comfortable, using that input to shape the care provided by the hospice team. The

## VA in the Vanguard of Improving End-of-Life-Care

Individual champions and facilities have advocated for hospice care in VA since the earliest days of the American hospice movement in the 1970's. National efforts to expand those isolated incidents into a more systematic approach to end-of-life care for the VA system received an important boost from Dr. Kenneth Kizer, VA Under Secretary for Health from 1994 to 1999. Different departments within VA's central office, including the Office of Academic Affiliations (OAA); Geriatrics and Extended Care Strategic Healthcare Group and Home and Community-Based Care, both within the Office of Patient Care Services; and Employee Education System, have made significant contributions to the emergence of a more comprehensive and coordinated approach to end-of-life care within VA.

In 1997, Kizer convened a VA End-of-Life Summit, bringing together experts and advocates to explore the issues. This led to the development of national outcomes measures reflecting greater accountability for appropriate end-of-life care; among these was the "Pain as a Fifth Vital Sign" initiative, an effort in which VA led the nation in recognizing and treating pain.

Since then, VA has conducted several projects aimed at improving quality, enhancing training and education for physicians and others involved in end-of-life care, and coordinating VA hospice and palliative care services. Funded in part from generous grants from national organizations interested in improving end-of-life care, they are:

◆ **VA Faculty Leader Project for Improved Care at the End of Life**, funded in part by a generous grant from the Robert Wood Johnson Foundation, identified and supported 30 faculty leaders to establish palliative care training curriculums within VAMC-based internal medicine residency programs.

◆ **Training and Program Assessment for Palliative Care (TAPC)**, supported by the Office of Academic Affiliations, included a national survey to identify and describe actual end-of-life care practices in VAMCs.

◆ **Interprofessional Fellowship Program in Palliative Care**. Administered by the Office of Academic Affiliations, these clinically focused fellowships are based at six competitively chosen VAMCs with experience in providing palliative care and each include one or two

physicians and two or three other health professionals. The hub for the fellowship network, in Palo Alto, Calif., also supports a web-based **VA Nationwide Palliative Care Network**.

◆ **VA Hospice and Palliative Care Initiative**, a two-year effort bringing together more than 40 VA and community leaders to design programs that would accelerate access to compassionate and coordinated hospice and palliative care services for all veterans. Rallying Points, a national program of Last Acts Partnership for Caring, joined with VA to extend VAHPC beyond its initial two years. Seed money was provided by the National Hospice and Palliative Care Organization and the Center for Advanced Illness Coordinated Care.

◆ **National Hospice-Veteran Partnership Program** (see p. 8), supported in part by Rallying Points, is actively promoting national, state and local collaborations among VAMCs, community hospices and other partnering groups to improve access to hospice and palliative care for all veterans.

◆ **Accelerated Administrative and Clinical Training (AACT)**, supported by Geriatrics and Extended Care in collaboration with the Employee Education System and the Office of Academic Affiliations, is a program designed to disseminate the knowledge being gathered through VA's end-of-life initiatives. AACT brought together and trained multidisciplinary teams from each of the 21 VA VISNs (Veterans Integrated Service Networks) to encourage palliative care program development in their networks.

VA is now working to hire central office staff dedicated to hospice and palliative care development. The first of three projected central office staff, Dr. Scott Shreve, began as **National Director of Hospice and Palliative Care Services** in June 2004. Shreve is continuing to work half time as medical director of the hospice unit at the VAMC in Lebanon, Penn., while promoting quality improvement throughout VA.

**Resources:** To view the Nationwide Palliative Care Network website and newsletter, go to [www.hospice.va.gov](http://www.hospice.va.gov). That site also contains a copy of the TAPC report. The TAPC toolkit and other end-of-life educational information are on the OAA website: [www.va.gov/oaa/flp](http://www.va.gov/oaa/flp). ■

# Collaboration Enhances Caring

## What's Different for Dying Veterans?

Through her experience as clinical coordinator of the pioneering inpatient hospice unit at the Bay Pines VA Medical Center in St. Petersburg, Fla., Deborah Grassman has closely observed some important differences and lessons for providing end-of-life care to veterans. "It's only in the past ten years that we have started to realize that many things can influence a veteran's death," she says. Factors influencing veterans' experiences at the end of life include age, whether enlisted or drafted, branch of service, rank, and combat or POW experience.

Grassman presents a powerful and informative educational session on how health care professionals can attend to those differences. She has given the presentation to rapt professional audiences locally, nationally and in a recent VA educational teleconference.

"If veterans have seen combat, they have seen horrific things," Grassman says. Some are able to integrate that experience into their lives and as a result may be better equipped psychologically to cope with their own deaths. "These veterans are role models for how to have a good death, and in a death-denying society, that's important," she says. Still others suffer from post-traumatic stress disorder (PTSD), with symptoms that can include social isolation, alcohol abuse, and anxieties.

For some veterans, the effect of combat experience may remain buried for years, emerging only when the veteran is very sick and dying. In these cases, veterans may experience anxiety, agitation and resurrected memories connected to war experi-

ences from many years before, Grassman says. Their medical caregivers need to differentiate these systems and treat them appropriately.

Doug Weadick, chaplain for the hospice unit at the Orlando, Fla., VA Health Center, has made similar observations. He notes, "When you're dying, you look back on significant events. Combat is a form of intimacy—very traumatic, life changing. It defined who they were and became. What I see is that they [veterans] want to process these events at the end of their lives."

Weadick says there is almost an audible sigh of relief for veterans who meet others like themselves on the hospice unit. "They're home—they're with people who have gone through the same things. They don't have to share their war stories. They just know the other person has gone down the same path."

Health professionals caring for veterans at the end of life should keep the following factors in mind:

- ◆ The demographics of veterans dying in the VA system, such as their higher degree of social isolation, lack of family support, or low income;
- ◆ The veteran's experience with military culture and the camaraderie of other veterans;
- ◆ A culture of stoicism that might prevent veterans from admitting to being in pain, or from asking for pain medication;
- ◆ The causes of terminal agitation, which may be related to PTSD or to disease-related terminal restlessness;

- ◆ Most dying people resist physical and chemical restraints—but for dying veterans, such restraints may be even more overwhelming; and
- ◆ The possibility of paradoxical reactions to medications.

"I've seen many variations on these themes," says Dr. James Hallenbeck of the VA Palo Alto hospice unit. "I try to teach doctors on our unit to establish a relationship that starts with respect for the veteran. They were part of an experience that those who weren't there can't imagine. For a lot of our veterans, it's just polite to say, 'What branch of the service were you in?' If you acknowledge that aspect of their lives, you have a better chance of establishing respect and a connection," he says.

"Be careful of the stereotype of the homeless Vietnam veteran on the street—just like the stereotype that all World War II veterans are like John Wayne or Audie Murphy," Hallenbeck cautions. "Let's not overstate the case. Not every veteran suffered terrible trauma." What's needed now, he adds, is research to study further the anecdotal experiences coming out of VA hospice units and to connect that with VA system's extensive experience treating PTSD. ■

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# and Expands Access

## How Can Community Hospices Collaborate with VAMC's?

Approximately 3,200 hospice programs operate in the United States. Large and small, non-profit and for-profit, independent and hospital-based, they serve 900,000 terminally ill patients a year, most in private homes or in skilled nursing facilities. Hospices assist family caregivers, and eventually provide bereavement support to family survivors.

VA hospice units have learned a critical lesson in caring for dying veterans: a patient's military service history is highly relevant to providing the most appropriate, personalized end-of-life care. Although hospices routinely ask and record their patients' age, family make-up, racial/ethnic group and religion at the time of enrollment, few ask about service status. But they should. There may be health coverage and benefit issues, if the veteran is enrolled at a local VAMC or would like to be, along with burial and other benefits. In addition to exploring coverage status, hospices should consider incorporating the following questions into their admission process:

- ◆ Are you a veteran?
- ◆ Did you see combat?
- ◆ What was that like for you?
- ◆ Is there anything about your military experience that is still troubling to you?

The National Hospice and Palliative Care Organization (NHPCO) has long advocated that veterans should receive hospice care and that community hospices should be reimbursed by VA for the care they provide to appropriate, eligible veterans, says Judi Lund Person, NHPCO's Vice President for Quality End-of-Life Care. "NHPCO will continue to strongly support this work and relationship-building as we look for funding opportunities to further advance the cause," she says.

In 2002 NHPCO contributed \$100,000 to the VA Hospice and Palliative Care Initiative and today it plays an active leadership role in promoting Hospice-Veteran Partnerships nationwide. NHPCO recently awarded \$5,000 grants to 10 state hospice and palliative care organizations to improve access to hospice care for veterans. Organizations in the Carolinas, Colorado, Connecticut, Illinois, Indiana, Kansas, Maine, Massachusetts, Michigan, and New York are integral parts of state Hospice-Veteran Partnerships, working with VAMCs and other partners to assess the needs of dying veterans and provide hospice education and outreach.

"We have all of these dying veterans and we want to make their lives better. We want to figure out how to get community hospices more involved, and how to overcome barriers to coordinated care, so that we can provide the best end-of-life care for veterans and their families by whatever means necessary," Person says.

"It's not just about getting paid, but at the same time, that issue has been a sticking point for hospices. Now it's possible for VA to purchase hospice services from community hospices. But hospices need to understand that partnering is a two-way street," she explains. Hospices, which routinely market their services to health care facilities and providers, must do the same to encourage referrals from VAMCs.

"When I gave a keynote presentation to the California Hospice and Palliative Care Association last year, hospices wanted to know how to enter the 'impenetrable monolith' of VA—and how to find the right people within that system," says Dr. James Hallenbeck, Director of Palliative Care Services for the VA Palo Alto Health Care System. Although

authorization for VA to pay for hospice care has existed for several years, individual programs may still encounter problems. These groups need to negotiate with VAMCs, using national guidelines, to work out kinks in the process at the local level.

Most important, Hallenbeck says, hospices should not approach VA as an insurance plan for covering hospice care in the community. They need to learn the subtleties of the relationship and recognize differences in language between the VA and Medicare.

"Hospices need to establish relationships and identify liaisons at both sides before individual coverage decisions are needed," he says. Find out which providers are dedicated to hospice and palliative care, and arrange to meet with them. The right person may be the palliative care consultation team coordinator, community health nurse or staff member on the hospice unit, if one exists in the facility.

"There are other nitty-gritty issues involved in the relationship, but these can be solved through conversation," Hallenbeck says. For example, VA physicians often are not accessible after 5 pm for emergency changes in medical orders. Since hospices require after-hours medical access, the hospice physician may assume this responsibility while preserving the VA primary care physician's involvement in the patient's care. These and other policy issues related to VAMCs working with community hospices are described in VA's new Handbook, "Procedures for Referral and Purchase of Community Hospice Care." Nearing completion, the handbook will be publicly available on VA's publications web page (<http://www.va.gov/pub/direc/health/publications.asp>). ■

character of the unit is also reflected in a cooked-to-order breakfast served each Wednesday to patients and families on the unit by Chaplain Dan Hummer and hospice volunteers.

Special “eleventh hour” volunteers can be called in to keep vigil for dying patients who would otherwise spend their final hours alone. One of these volunteers, Judy Dellerba, says, “I feel it is an honor and privilege to be there with them.” Dellerba’s own husband died on the unit two years ago, and the hospice grief support program helped her through the period following his death.

### Meetings Without Agendas

John Cornhoff, an 87-year-old World War II veteran dying of end-stage dementia and pneumonia, is surrounded by several generations of his family, from children to a great-grandchild. Those not present in person have been brought in by speakerphone. Hospice staff members join them for a quality-of-life meeting.

Cornhoff’s boisterous, obviously loving family recently made the decision not to have a tube inserted through his nose into his stomach for artificial nutrition and hydration. Grassman suggests that their decision may be helping him to die more peacefully. She points out that he now seems to be turning inward, a sign of approaching death.

“The body has its own wisdom,” she says. “We’re just honoring what’s happening to John, a very holy process to which we want to bring dignity.”

Each of Cornhoff’s assembled loved ones speaks in turn to reminisce and say goodbye with a mixture of laughter and tears.

“Dad has always lived life to the fullest,” says older daughter Peggy, who sits on her father’s bed to be near him. “He taught us to enjoy life and each other. He accepts people the way they are. We go forward, we don’t go backward.”

Over the speakerphone, son-in-law Tom asks, “Are you listening to this, Dad?” Eyes closed, mouth open, laboring over each

### Hospice-Veteran Partnerships Promote Access

With support from VA headquarters, the National Hospice and Palliative Care Organization, the national Rallying Points office in Washington, D.C., the Center for Advanced Illness Coordinated Care in Albany, N.Y., and other end-of-life advocates, Hospice-Veteran Partnerships are now forming at state and regional levels to increase access to appropriate end-of-life care for veterans. They promote access by strengthening partnerships between VAMCs and their community partners, and by expanding their mutual knowledge base.

Some states are already well advanced in this dialogue while others are just starting to talk. A Hospice-Veteran Partnership “Toolkit” developed by the VA Hospice and Palliative Care Initiative and published by Rallying Points is full of suggestions for how to do this. Partnerships often are co-sponsored by state hospice organizations while bringing together community hospices, community end-of-life coalitions, veterans’ service and alumni organizations, private service clubs, state Departments of Veterans Affairs, state veterans homes, the National Cemetery Association, local military treatment facilities, and VA professionals at the medical center and VISN levels.

“So much can be accomplished just by sitting around the table and talking with each other,” says Kathleen Jacobs, Rallying Points Regional Resource Center Coordinator based at The Hospice of the Florida Suncoast in Largo. From there, coalitions typically assess unit local needs, develop a strategic plan for how best to serve veterans in the area, and then share information with veteran groups and the public. “Florida is a prototype of what can be done through partnerships,” Jacobs says.

The Florida state group designed Hospice-Veteran Partnership commemorative pins with a card that reads, “Thank you... for your military service to America by advancing the universal hope of freedom and liberty for all.” It distributed 20,000 of these pins in November 2003 to VA facilities, community hospices, veterans’ organizations, and public officials, as well as at a number of commemorative events.

“These events helped to bring greater awareness to end-of-life issues and the need for advance care planning, without seeming morbid,” says Joanne King, director of social work for Hospice of Volusia-Flagler in Port Orange and a member of the Hospice-Veteran Partnership of Florida. The coalition also co-sponsored a February 2004 statewide professional education teleconference on end-of-life care for veterans.



John Cornhoff, a terminally ill World War II veteran, shares a peaceful moment with his daughter Peggy in his room on the Hospice Unit at Bay Pines VA Medical Center in St. Petersburg, Florida

“We gather like this to be with you and hear what’s on your hearts and minds. We don’t have an agenda,” Grassman begins. In accordance with his expressed wishes,

breath, head bent on the pillow, Cornhoff nods perceptibly. Someone describes this to Tom, who jokes, “Can I have the ten bucks you owe me?”



In another room on the unit, another patient's family has a smaller, more subdued quality-of-life meeting. Matthew Civilette, 77, and his only living daughter, Fran, meet with the hospice team. Civilette, who has kidney cancer, saw extensive action in the Philippines during World War II. With a resigned look on his face, Civilette says he's ready, almost impatient to die. Just a week ago, he was up, and dancing at the assisted living facility where he had been living.

"The quicker I go, the better. I've had a good life. I'm 77 years old. Nobody escapes," he says.

"We had breakfast together this morning at quarter to six, my usual time," Civilette informs the team, nodding to his daughter. "They promised scrambled eggs and toast and they delivered."

"And he sat up and ate them," Fran adds. After a bit of reflection, she says, "I'm upset about losing my dad, but it happens to all of us. What can you do?"

"I'll still talk to you after, if I can figure out how," Civilette tells his daughter. "I'm glad you brought me here [to the hospice unit]. It's very pleasant."

The next day, Civilette died in the way he had hoped: peacefully, quickly, and with his daughter at his side. Grassman later reported, "Fran touched him and told him that she loved him as he took his last breath."

## Shared Vision, Shared Work: VA and its Hospice Partners

Under the leadership of CEO Mary Labyak, The Hospice of the Florida Suncoast (The Hospice) has become the largest and best-known nonprofit hospice program in the country, serving some 1,600 terminally ill patients each day. From its Pinellas County headquarters, The Hospice operates a national education institute and provides a broad range of community outreach programs, successfully weaving its care into the fabric of the retirement communities of greater St. Petersburg. The communities it serves also lie within the service area of Bay Pines VAMC. Although both groups share similar goals, until recently, they had not mapped out ways to work together and learn from one another.

The realization that this was necessary came when Deborah Grassman gave her groundbreaking educational presentation on the different experiences and needs of combat veterans at the end of life (see p. 6) to staff at The Hospice. Many staff had not realized that veterans had unique experiences and needs, and that care could be designed to accommodate those needs.

"You see people with 20 to 25 years of hospice experience—like me—realizing that there are big parts of people's lives we somehow missed," Labyak says.

***"You see people with 20 to 25 years of hospice experience—like me—realizing that there are big parts of peoples's lives we somehow missed... It's a huge step forward for access and quality for community hospices just to be having the conversation with VA about what's different for veterans."***

Mary Labyak, CEO, The Hospice of the Florida Suncoast

"There needs to be a call to action for hospices about why the unique needs of veterans are important," Labyak says. "It's not just about reimbursement. It's a huge step forward for access and quality for community hospices just to be having the conversation with VA about what's different for veterans."

"Precipitated by Deborah's phenomenal presentation, we have started thinking here in new ways about patients in pain, about terminal restlessness. It has become a wonderful learning experience for us, tapping a rich new vein for our professional practice and reinforcing our mission."

## Volunteers Play a Role in Hospice

Ed Chaffin, 57, is a volunteer on the inpatient hospice unit at Bay Pines VAMC in St. Petersburg, Fla. (see p. 5). "I am a Vietnam vet. I was there from 1967 to '68, and when I was there I saw a lot of action," he says. Some might feel it was too much: at one point, Chaffin's job was to clear the battlefield of soldiers' bodies. He says that he can never forget one body that he had to leave behind because the man's legs came off in Chaffin's arms. That experience led to a commitment that he would not let other veterans die alone.

"Ed comes in here almost every day, sits at the bedsides of dying patients, sometimes in total silence, just being a presence," relates Hospice Chaplain Dan Hummer.

Chaffin's long path from Vietnam to hospice volunteering led through the orthopedic ward for his war injuries, knee replacement surgery with complications that nearly killed him, a post-traumatic stress disorder clinic for depression and panic attacks, support groups, and, finally, with his wife's encouragement, for him to volunteer.

"I've been volunteering up here on the hospice unit for three years. It really helps me. It goes back to the guy I left behind", Chaffin says. "It's therapy for me, although other vets I talked to think that I'm crazy." He discovered that terminally ill veterans will talk to another veteran more easily than to a non-veteran. "When they bring a new patient up here, I'm the first one in after the nurse. A lot of times the people I visit, they don't have anybody," he says.

Volunteers are an essential component of all hospice care; in fact, Medicare-certified hospices must use volunteers. Hospices tend to rely on volunteers for more intensive, one-on-one contacts with patients and families than is typical for other VA volunteer services. Hospices may recruit volunteers from many sources: Family members of patients who died in a hospice unit, military spouses or retired military and pre-med or nursing students. But as hospice care grows within VA and as community hospices increase their effort to respond to the needs of veterans, the demand for the humanizing presence of veteran volunteers is certain to grow. Experts say one important untapped resource for support and manpower are veterans' service organizations.

The Hospice of the Florida Suncoast and the Bay Pines VA hospice unit have developed their relationship, working through designated staff liaisons and learning from each other, says program director Marcie Pruitt. Primary care physicians at Bay Pines can refer to The Hospice, and its after-hours physician coverage, without having to sever their link to their patients, while Bay Pines contracts with The Hospice to offer a bereavement support group on the unit. A key focus for their collaboration is managing the transition of veterans who are referred to The Hospice for care at home but eventually return to Bay Pines VAMC for longer-term inpatient care on its hospice unit.

An example of such give-and-take is Paxson (Pax) Parsons, a 55-year-old Vietnam veteran who is dying of lung cancer. Parsons is enrolled with The Hospice and receiving care at a quintessential Florida ranch-style house that he bought and refurbished shortly before his cancer was diagnosed. He lives alone, visited by a circle of friends, but plans to return to the Bay Pines hospice unit when he gets closer to the end. Parsons explains his plans and his history with the VA on a visit to his home with his hospice counselor, Harriet Hoke.

He projects a striking image with his shaved head, piercing eyes, rainbow-striped kimono, gold neck chains and a nasal cannula hooked around his ears. The cannula is attached to an enormous length of rubber tubing, which allows him to wander freely around his house and back to his pool while remaining connected to the oxygen dispenser.

## A Painful Eye Opener

Parsons was 21 years old when he was sent to Vietnam. "When we were flying in, they told us to put our heads down. Well, it is a big deal when you start getting shot at," he says. Parsons returned state-side in 1970 with physical and psychological disabilities that required care from VA. In those days, he says, "you really had to fight for what you needed."

Indeed, Parson was eventually confined to a psychiatric hospital and later treated

for drug addiction. He has been in recovery for 20 years and is enrolled in a VA stress management program for PTSD. "I've gotten better thanks to the Bay Pines VAMC. They helped me because they treated me like a person," he observes.

"My life really began after Vietnam. 'Nam was bad, but it opened my eyes," Parsons says. "Once you've been in a war zone, your life changes like that (snap). I was born Southern Baptist and I was gay. Surprisingly, my family is very accepting of me now. I love who I am and who I became. Even my two daughters have come a long way with that," he relates.



"I went into the Carolina mountains, got my life together and got off drugs," he continues. He explored spiritual traditions, including Native American healing—he's part Cherokee—spirit guides and the 12-step acknowledgement of a higher power. "I discovered a whole new me—*Pax*, not Paxson. I left Paxson back in Vietnam. He's scary. You don't want to meet him," he warns.

Eventually, Parsons took charge of his own life, helping to establish an HIV volunteer program in Delaware in the 1980s. This experience of working with dying people changed his view of dying. "That's why I'm not afraid of death. Because of the whole war issue and what I

went through, it made me feel the pain of other people," he says.

Parsons has since helped many veterans negotiate their benefits and complete the necessary paperwork to obtain VA services, while supporting others to become more accepting of who they are.

He encourages other veterans with life-threatening illnesses to be open to hospice care. "It's a lifeline," he says. "You'll be a lot more comfortable. It's not about dying—that part's up to you. Hospice is just a helping hand, helping you live with the disease. It's helped me a lot."

Vietnam veteran Paxson Parsons is a striking presence and memorable storyteller despite the lung cancer that has placed him under the care of The Hospice of the Florida Suncoast in Largo.

**Epilogue:** Pax Parsons never made it to the Bay Pines VAMC unit. His lung cancer advanced more quickly than expected, so his partner, Don, and his sister, who was staying with him, decided to try to keep him at home. On March 14, a month after the writer's visit, he was still up and walking around the serene, art-filled home that gave him so much comfort, although increased breathing difficulties and inability to swallow pills signaled a decline. The next day he died at home, comfortably and relatively free of pain, in the company of loved ones and attended by his spirit guides.

Across the country on May 26, Stephen Pavon died on the hospice unit at the Palo Alto VAMC, peacefully and comfortably. ■



Veteran John Cornhoff's family joins together (some of them long distance by speakerphone) for a quality-of-life meeting at the Bay Pines VAMC

## Dedication and Acknowledgments

We dedicate this monograph as a loving tribute to Marsha Goodwin, RN, MSN.

The remarkable progress VA has made in advancing end-of-life care was made possible by the dedicated leadership and compassionate support of Marsha Goodwin. During her years in the Geriatric and Extended Care Strategic Healthcare Group in VA Central Office, Marsha provided skilled guidance, articulated core values and initiated enduring actions that led to the tremendous advances made throughout the nation to ensure access to hospice and palliative care for the veterans we are privileged to serve.

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Cancer patient Stephen Pavon reflects on a full but restless life as he confronts its approaching end from the peaceful vantage of his hospice room at the VA Medical Center in Palo Alto, California.

