The VA Advances End-of-Life Care by Focusing on Veterans’ Unique Needs

By Audrey Doyle

“You matter because you are you, and you matter to the end of your life. And we will do all we can, not only to help you die peacefully, but also to live until you die.”

These words are attributed to Dame Cicely Saunders, the English nurse, physician and writer who founded the modern hospice movement in the United Kingdom in the late 1960s. They also represent the guiding principle for how the U.S. Department of Veterans Affairs (VA) meets the needs of military veterans at the end of life.

“Veterans face unique issues that are products of war and of the violence that was perpetrated on them, or that they perpetrated on others out of necessity,” said Dr. Karl Lorenz, chief of palliative medicine at the VA Palo Alto Health Care System (HCS) in California. At the end of life, these issues—feelings of intense guilt and responsibility, fear, anger, anxiety, stress—can rise to the surface, causing veterans to wrestle with profound emotions they may have buried for decades.

The VA attends to issues such as these by offering hospice and palliative care services tailored to veterans’ needs, making it a priority to understand how best to care for each veteran as they cope with end-of-life challenges. “We do everything in our power to enable our veterans to live until they die,” said Dr. James Hallenbeck, director of palliative care and associate chief of staff for extended care at the VA Palo Alto HCS, and associate professor at the Stanford University School of Medicine. “Our goal is to help them be all that they can be until the moment they pass away.”

It’s a goal the VA has been achieving for nearly 40 years. The national VA health system started offering hospice and palliative care to veterans and their families shortly after the hospice movement took hold in the United States, with the opening in 1979 of the Palo Alto Hospice Care Center, a dedicated unit within the VA Palo Alto HCS.

Today, the VA Palo Alto HCS, which is affiliated with the Stanford University School of Medicine, is one of approximately 140 VA medical centers in the country where specially trained teams of physicians, nurses, chaplains, social workers and mental health professionals deliver hospice and palliative care to veterans in VA hospice units and community living centers. The hospice care is focused on quality of life and is offered to veterans with limited life expectancies; the palliative care is focused on improving quality of life and relieving distressing symptoms and is appropriate for veterans at any stage of their illness. The VA also partners with community and state hospice agencies and organizations to arrange care for veterans at home or in another non-VA facility. Both hospice and palliative care services are covered benefits for all enrolled veterans.

Honoring Veterans through Targeted Strategies

The expansion of hospice and palliative care capabilities at the VA occurred largely as a result of the VA Hospice and Palliative Care (VAHPC) initiative, which was established to ensure high-quality end-of-life care and coordinate care services both within and outside the VA.
The initiative also focuses on enhancing training and education in end-of-life care for veterans. For example, the VA partnered with Northwestern University’s Feinberg School of Medicine on a program called EPEC for Veterans (EPEC stands for Education in Palliative and End-of-Life Care), and it worked with City of Hope, a research and treatment center for cancer, diabetes and other life-threatening diseases, on a program called ELNEC for Veterans (ELNEC stands for End-of-Life Nursing Education Consortium).

The curricula in these clinician and caregiver training programs focus on topics such as ethics and law in end-of-life care, goals of care, palliative care nursing, communicating difficult news, pain and symptom management, cultural and spiritual considerations in palliative care, psychological issues, final hours of living, and loss, grief and bereavement. The VA also collaborated with the National Center for Ethics in Health Care on a goals-of-care conversation training program aimed at providers.

Also as part of the VAHPC initiative, the VA works with the National Hospice and Palliative Care Organization (NHPCO) to build Hospice-Veteran Partnerships (HVPs) with hospice and palliative care providers around the country.

Funded in part by the VA, the NHPCO, the Advanced Illness Care Coordination Center and other nonprofit groups, the HVPs are coalitions of VA facilities, community hospices, state hospice organizations and other end-of-life care organizations that provide leadership, technical assistance and program development recommendations targeted at veterans and their families. In addition, the VA Office of Geriatrics and Extended Care implements a Veteran Community Partnership (VCP) model that provides opportunities for HVPs to address veteran-related issues upstream in the continuum of care in addition to end-of-life care.

### Addressing Veterans’ Unique Needs

Currently, the HVP program is implemented as part of *We Honor Veterans*, a program of the NHPCO and the VA through which staff and volunteers at community hospices and state hospice organizations receive education as well as tools developed to address issues specific to veterans facing life-limiting illnesses.

One such tool is a military history checklist the VA developed for hospice agencies to use on patient intake/admission to identify whether the patient is a veteran and, if so, to evaluate the impact of their experience. Veterans are asked such questions as what war they served in, what branch they served in and whether their service included combat or other dangerous and/or traumatic assignments.

Each question has implications. For instance, the military branch in which veterans served can sometimes determine their likelihood of having experienced combat-related trauma. The assignments that veterans completed are relevant because even veterans who didn’t experience combat may have been responsible for performing traumatic tasks such as transporting body bags or recording names of service members who were killed in action.

Asking what war veterans served in is particularly important, as the answer to this question can yield additional crucial insights regarding care needs. “For example, World War II was a very publicly supported war and veterans were often considered heroes when they arrived home, whereas the Vietnam War was a very long and contentious war and veterans were not welcomed back,” said Dr. Carol Luhrs, acting national director, VA Hospice and Palliative Care.

In addition, Vietnam veterans were often in immediate physical danger and had fewer areas of safe haven than World War II veterans, so they typically experience more stress-related issues. And many veterans of the Korean War were POWs who were subjected to horrific forms of torture and other abuses, the memories of which they may have buried as a way to deal with the stress and trauma they experienced.

“It’s not unusual for veterans not to want to talk about their war experience when they come home—it’s their coping mechanism. But as the dying process unfolds, they tend to want to talk about what they went through,” said Dr. Hallenbeck. Through the military history checklist, hospice caregivers can initiate conversations with veterans about their combat and related experiences to help them manage their feelings of guilt, anger and other emotions.

Another common coping mechanism is social withdrawal and isolation, which can occur among veterans who feel they should be able to deal with their challenges and struggles on their own. When these veterans become ill and suddenly depend on care from others, they can become angry and agitated and even act out, according to Dr. Hallenbeck.

In these cases, caregivers are taught through *We Honor Veterans* to acknowledge the veteran’s distress in no longer being able to live independently, and to ask what they can do together to maximize the veteran’s sense of freedom and control. “Sometimes the best way to deal with a raging bull is to offer a big pasture,” Dr. Hallenbeck said, adding that encouraging struggling veterans to be in charge of what they can control can help guide them toward a more peaceful end.
In addition to issues specific to service members, *We Honor Veterans* also guides caregivers in issues specific to families surrounding their loved one’s end-of-life experiences. “For example,” said Dr. Hallenbeck, “when dying veterans start to talk about war experiences they never talked about before, family members will ask whether something’s wrong, since their loved one never opened up about these experiences.”

For such cases, the VA ensures that those providing care to veterans also receive education surrounding family support—in this case, explaining to families that it’s not uncommon for dying veterans to open up about their war experiences, and providing them with chaplains, mental health workers, psychologists and social workers to talk to about their feelings. And because hospice care is centered on families as well as patients, caregivers are taught how to discuss end-of-life decisions with family members and how to care for family members in their grief.

**A Heartfelt Thank-You**

As important as it is to address the struggles and challenges that many of our nation’s veterans may be facing at the end of life due to traumatic experiences they suffered during their time in service, the VA also advocates the importance of simply recognizing and thanking veterans for their service. Toward that end, *We Honor Veterans* educates caregivers on ways to show veterans that their service was appreciated.

“Performing certain rituals is very comforting and special for veterans and their families,” said Dr. Luhrs. “For example, we have pinning ceremonies where we thank veterans for their service. This is particularly moving for Vietnam veterans, many of whom have never been thanked or recognized.”

Also, when a veteran dies in a VA or community hospice facility, staff and patients line the hallway and stand in silence, or salute if appropriate, as the veteran leaves the facility on a gurney draped with an American flag. “It’s very much appreciated by the veteran’s family, and by the other veterans who see it as a way to honor their fallen comrade,” said Dr. Lorenz.

Currently, the VA is working with the National Center for Ethics in Health Care on a major quality improvement project called the Life-Sustaining Treatment Decisions initiative. The goal of the initiative is to promote personalized, proactive, patient-driven care for veterans with serious illness by eliciting, documenting and honoring their values, goals and preferences. The initiative involves a national policy to standardize practices related to discussing and documenting goals of care and life-sustaining treatment decisions, and the tools, resources, education and monitoring to support clinicians and facilities in making practice changes.

Also with an eye toward quality improvement, the VA administers surveys designed to yield actionable information reflecting the quality of care delivery from the perspective of family members. For example, the Bereaved Family Survey, developed by the VA’s Center for Health Equity Research and Promotion, is a National Quality Forum–endorsed survey focusing on aspects of care the veteran received at a VA inpatient facility during the last month of life. Performance areas evaluated include communication, emotional and spiritual support, pain management and personal care needs.

Meanwhile, to help hospices evaluate the care they delivered to their veteran patients, the VA collaborated with the NHPCO to develop Veteran-Specific Questions (VSQs). This post-death survey asks family members whether the staff used the military history checklist, how often staff took the time to listen to the patient’s stories and/or concerns related to their military experience, and how much help the patient received in dealing with emotions resulting from combat-related stress.

As America’s veteran population continues to age, the need for high-quality end-of-life care will continue to grow. According to the VA, approximately one out of every four Americans who die each year is a veteran. Most of them are veterans of World War II; now in their late 80s and 90s, these servicemen and women are nearing the end of their natural life spans. However, with Korean War veterans approaching their mid-80s and Vietnam vets entering their 70s, that death rate will likely remain the same for the next five to 10 years, said Dr. Luhrs.

“End-of-life care is a choice, and not every veteran chooses it,” concluded Dr. Hallenbeck. “By tailoring end-of-life care to what is appropriate for veterans, we’re better serving those who do.”