Family Caregivers Play Vital Role

Serious disabilities such as amputations, brain injury and spinal cord injuries don’t just affect the veteran; they also affect the family of the survivor. In many cases, it is up to family members to take care of the physical, emotional, economic and social needs of the veteran.

National Commander Bobby Barrera often talks about the vital role of family in his recovery and rehabilitation from injuries he sustained in Vietnam. And as the wars in Afghanistan and Iraq and beyond remind us, the sacrifices made by our brave men and women in uniform also have a profound impact on their families as well.

“It is often said that when servicemembers go to war, their families also ‘go to war’ in a very real sense,” said National Adjutant Arthur H. Wilson. “And when veterans return home, often with severe injuries, their lives and the lives of their family members are forever changed.”

There has always been a need for family support, both during deployment and afterward. And when veterans return from the battlefield, the entire family goes through a period of
transition. Experts agree that this is the most important time for the family to seek support and learn about the changes and difficulties that may occur, especially if the veteran has a severe injury.

It is widely recognized that informal caregiving can delay or prevent a veteran from being institutionalized, and these caregivers relieve VA of the obligation and the cost of institutionalization. This also results in an enhanced quality of life for the veteran.

“Of course, the VA’s patient medical care and rehabilitation are among the very best available, especially when it comes to polytrauma, traumatic brain injury and the like,” said Washington Headquarters Executive Director David W. Gorman. “But the VA also knows that family and friends have an important role in helping disabled veterans get the most out of their rehabilitation.”

While the VA’s programs and support for family caregivers continue to evolve and expand to meet a growing need, those efforts face a number of challenges. Among them are statutory restrictions on VA’s authority to provide direct services and support to family caregivers as well as funding limitations. Nevertheless, the VA has made strides toward providing more options for care and through contracts with existing programs.

For example, the VA reports that it currently contracts for caregiver services with more than 4,000 home health and similar public and private agencies. The contractor trains and pays the caregiver directly. But those caregiver services are not part of the veterans health benefits package; they are only provided upon request.

In addition, the VA’s Volunteer Caregiver Support Network program is a collaborative effort between VA Voluntary Service and the Office of Care Coordination. Its Volunteer Respite Program prepares volunteers to assist primary caregivers of
veterans. Through this program, volunteers are trained by peers and health professionals to provide a much-needed temporary break for family caregivers. The local VA Voluntary Service Specialist has primary responsibility for establishing and operating a community-based volunteer home respite program for primary caregivers, but they are not available at all medical centers.

“While family members certainly need some time off from their caregiver duties, such volunteer respite programs are no substitute for a full range of support services the VA ought to be providing throughout the system,” Gorman said.

In 2006 Congress authorized funds for new VA caregiver assistance efforts. And in December 2007, the VA announced the allocation of $4.7 million to help fund eight pilot programs across the country to explore innovative options for providing education and support services to caregivers. These two-year projects included respite care, case management and service coordination, assistance with personal care, extended days of respite care, social and emotional support and home safety evaluations. They also included teaching caregivers how to obtain community resources such as legal assistance, financial support, housing assistance, home delivered meals and spiritual support.

“The VA is in the process of reviewing the outcomes of these new caregiver pilot programs, and the DAV eagerly awaits the results of that study,” said Gorman. “

VA Vet Centers also are part of caregiver support efforts. Centers around the country offer veterans support for mental health needs, readjustment issues, marriage and family problems. Some even offer support groups to help caregivers better understand the veteran’s personal challenges. For those who live in rural areas, the VA also is networking with county and private human services providers to offer education and counseling and other support for caregivers.
“Unfortunately, many of the VA’s caregiver programs are just getting started,” Gorman said. “Family caregivers do not receive sufficient support services or financial assistance from the government, and the VA is limited as to the kinds of services it is authorized to provide to veterans’ family members.”

The DAV has long advocated for a comprehensive set of support services that will benefit these family caregivers and the veterans who need assistance.

“What is needed is an array of support services such as respite care, financial compensation, vocational counseling, basic health care, relationship, marriage and family counseling and mental health care. These services are essential to equip caregivers while they provide for our disabled veterans. Additionally, the VA should develop a ‘Caregiver Toolkit’ that includes a detailed recovery roadmap to assist them in maneuvering the complex systems of care and inform them of available federal, state and local resources,” Gorman said.

“Although the VA has the potential to be an even more essential resource for disabled veterans and their families, caregivers often have to find these kinds of services and valuable information from other sources,” said Gorman. These include other government agencies, nonprofit organizations, such as the DAV, and private businesses.

“The DAV understands caregiver support services fall under VA’s long-term care program, but there are significant gaps in VA’s existing medical benefits package that must be filled,” Gorman said. “We urge Congress to address the unequal eligibility for long-term services that has such a profound impact on family caregivers, and we urge that the VA abandon its one-size-fits-all approach to long-term care that unfairly limits the use of and access to such care.”
As a way to help fill those gaps, many families of veterans often turn to self-help books for advice in caring for persons with severe disabilities, such as those available from organizations, including the National Family Caregivers Association and the Family Caregiver Alliance.

Educational institutions and private publishing companies also have found a market for books to meet this growing need.

Demos Medical Publishing, among others, offers several practical self-help guides for patients and caregivers that attempt to bridge the gap between consumers and the health care community.

The following are some recent titles from Demos, which are distributed by Publishers Group West and are also available through Amazon.com, BarnesandNoble.com and all major bookstores. Those interested may also visit the Web site www.demosmedpub.com for more information.

The Mayo Clinic Guide to Living with a Spinal Cord Injury: Moving Ahead with Your Life, is an illustrated, accessible guide to help enable people with spinal cord injury return to an active and productive life within the limits of their disability. Leading medical experts at the world-renowned Mayo Clinic offer their expert advice on topics ranging from emotional adjustments to skin care to modifying a home and car to accommodate a disability. This book encourages readers to resume their favorite hobbies, participate in athletic activities and return to the workplace, if possible.

There are 1.7 million regular wheelchair users in the United States. Like anyone else, they work, marry, have children, travel, play sports and are full members of their community. Life on Wheels is an A-Z guide for information about living with mobility impairment. This book is designed to help people make their adjustments sooner and more completely by explaining how one adapts to disability, and by addressing
misconceptions that only delay the ability to adapt. This book is for persons using a wheelchair and those who share their lives with someone in a chair.

More than 1.4 million people sustain a brain injury each year in the United States. Add to that the number of returning veterans with a brain injury and the numbers are staggering. The Brain Injury Survival Kit: 365 Tips, Tools & Tricks to Deal with Cognitive Function Loss aims to give brain injury survivors, their families and loved ones the strategies they need to improve brain function and quality of life. The book is a compendium of tips, techniques and life-task shortcuts that author Cheryle Sullivan has compiled from her personal experience. From basic principles to unique solutions for saving time and energy, this book provides helpful information for those coping with the special challenges of a brain injury.

“The types of injuries that veterans sustain are in many cases so severe that family members put their own lives on hold to care for their loved ones. Many military and veteran families face financial and emotional hardships as they help their wounded sons, daughters, husbands and wives. We owe these families the support needed to care for our disabled veterans by providing family caregivers increased federal assistance,” said Gorman.