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Caregiver Michelle Briggs talks with her husband Bob in Hillsboro, Iowa.

Conference Focuses on Caregivers' Needs

By Thom Wilborn & Joseph R. Chenelly

Carol Martin found her relationship with her son, Jason, changed dramatically after he suffered severe brain injury in a car crash while stationed in Texas. "We actually grew apart," she said. "I had to develop a different way of dealing with my son."

Simona Valeri's marriage to Brian Isenhour also changed when he suffered traumatic brain injury while stationed in Italy. "Everything changed," she said. "It was like a big rock fell between us."

Both are full-time caregivers for their veteran loved one, experiencing all the joys and problems associated with that role. They told their stories, sometimes interrupted by tears, at the 2010 VA Conference Supporting Veterans at Home.

"Their insight into what is required to care for a veteran loved one shows the importance of the new Caregivers and Veterans Omnibus Health Services Act," said Washington Head-

quarters Executive Director David W. Gorman. "DAV spearheaded grassroots support for the legislation, which provides many services and benefits to help family caregivers."

The caregivers' personal experiences were both emotional and hopeful. They discussed the sacrifices made for their loved one, the isolation they suffer, the burnout and the dire need for medical training and financial support, all of which are addressed in the Caregivers Act. They also expressed joy at the rapid improvement of their loved ones thanks to the care they are able to provide.

The conference in Arlington, Va., was a national training session to educate VA clinicians and related health care professionals, researchers, administrators, as well as federal, state, and local officials and veteran service organizations. Its purpose was to highlight initiatives and best practices in support of veterans and their families who provide care at home.

Martin told conference participants that she was determined to give

her son as normal a life as possible. "The biggest challenge was sitting there and not being able to talk to him," she said. "He physically could do nothing."

Valeri said her husband had to "re-learn everything: smiling, talking, eating. You just keep going, getting through things."

Grace Benns, who cares for her husband, Eddie, has watched his health slowly deteriorate over the past ten years because of disease. At 73, she is five years older. "I have my own limitations," she said. Much like Martin and Valeri, Benns said she feels isolated with few friends or family members willing to offer the help needed.

Caregiving is a full time job, according to Martin. "Our friends have taken a back seat," she said. Valeri said she and Brian have good friends who help, "but friends are only friends."

"I think one of the most important supports for us is the Caregivers Act and the ability to get training," said Martin. "I think if I had medical

training from the time [her son] came home, I could have given him better care.” She also said that the VA could help with counseling in the home environment. “It would have been really good for the issues we faced.”

“We definitely need some kind of support from the VA when we get our loved ones home,” said Valeri.

“The VA has been truly good to me,” said Martin. “They should understand that helping us ... in the long run is doing it for the veterans. We need short-term help during the transition of the veteran coming home, and we need counseling at home.”

Dr. Madhulika Agarwal, chief of VA’s Patient Care Office, said caregivers need education, training and support. “It is important to focus on caregivers’ health,” she said. “Sharing information and knowledge reduces the caregivers’ isolation. Classes and increased communications between caregivers decrease the stress, anxiety and anger and increases well-being and quality of life for the caregiver.”

Many caregivers report their own health deteriorates as a result of giving care, said Gail Hunt, president and CEO of the National Alliance for Caregiving. About 44 percent say their health has gotten moderately worse. More than half say their health decline has also affected their ability to provide care. Stress and depression are major problems suffered by caregivers.

“Veteran-centered care by the VA really has to include the family,” said Hunt. The average age of a veteran patient requiring a caregiver is 69. “More than 60 percent of younger veterans live alone, and 89 percent of

all veteran patients are men,” she said.

Caregivers spend an average 29 hours per week caring for their veteran loved ones, and only a small percent receive any formal training. “Caregivers of younger veterans are twice as likely to get financial help from the VA and other government agencies,” said Hunt. “Caregivers for veterans 50 and older are half as likely to seek financial help.”

“Caregivers sacrifice many ways for their veteran loved ones,” said Gorman. “Nearly seven in ten make workplace accommodations to provide the care needed by their loved one. It can be an economic catastrophe. But the Caregivers Act is going to assist those who sacrifice jobs and careers to give the best care to those who sacrificed for our country.”

Meg Campbell-Kotler, manager of the Office of Education for the Defense and Veterans Brain Injury Center, spoke about a new resource for caregiver training. This training curriculum, *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans*, can be downloaded at www.dvbic.org.

“A lot of people have put a great deal of work into creating a comprehensive set of tools to best support caregivers in their care of service members and veterans with TBI, Campbell-Kotler said. “It provides guidance and education to family members on traumatic brain injury (TBI) symptoms and their management while assisting the caregiver in communicating with members of the health care team.”

The curriculum mixes online and printed training materials and is broken

into four modules. The first covers the causes, types, diagnosis and treatment of TBI, as well as possible complications and the recovery process.

The second module focuses largely on the effects and treatment of TBI, noting potential impact on the patient’s physical and cognitive well-being.

The third module teaches the caregiver how to become an effective advocate for the patient.

“Often we find caregivers putting their own needs so far behind their injured loved one’s needs that they eventually cannot be effective because they become ill,” Campbell-Kotler said. “The entire family has to remember they have to take care of themselves, too.”

The fourth module is titled “Navigating Services and Benefits.” It covers health benefits, counseling, behavioral health, employment, housing, education, transition assistance and state benefits. It also explains the disability evaluation system and potential legal issues.

Each caregiver is given a “Caregiver Companion.” This prepackaged resource includes a glossary of medical and TBI terms, medication logs, contact information for members of the health care team and a home care team volunteer form. The guide is available online at www.traumaticbraininjuryatoz.org.

“We are very excited about this. It is going to put very useful information and tools into the hands of those who are doing such great things for America’s heroes,” Campbell-Kotler said. “The caregivers are heroes, too.”