

Military family members are stepping up to care for wounded veterans — but are we giving them the support they need?

By Kenya McCullum

Illustration by

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*facing
their
own*
Challenge





IT'S NOT SURPRISING EVERYTHING CHANGED WHEN JOSEPH BRISENO'S SON, JAY, AN ARMY RESERVE SPECIALIST, WAS INJURED IN IRAQ after being shot in the back of the neck in 2003. Jay, who was left blind and paralyzed from the shoulders down, needs constant care — including breathing assistance from a ventilator and being turned over about a dozen times a day — so Joseph Briseno and his wife dropped everything, including their careers, to provide that care to their son.

“Before this happened, our life was like any other normal people — go to work five days a week, get a weekend off, plan for retirement or vacations, and all of those things,” says Joseph Briseno. “But after this happened, we haven’t been on any vacations, there’s no more plans for retirement, and our savings have all been emptied.”

This is a common challenge many caregivers face: According to a survey released in 2010 by the National Alliance for Caregiving, caring for a wounded warrior can have a significant impact on people’s professional lives, and 59 percent of these caretakers have stopped working since they began providing care for a loved one. In addition, between 19 and 37 percent of caregivers who still work outside the home report they’ve voluntarily taken a reduction in pay and benefits in exchange for the flexibility they need to care for an injured veteran. And while their pay might get reduced, the medical expenses of caregivers increase exponentially. In fact, RAND Corp. — a nonprofit organization known for its public policy research — estimates out-of-pocket medical expenditures for family caregivers are 2½ times greater than those of their non-caregiver counterparts; VA services support only a small portion of an estimated 1.1 million caregivers nationwide.

Although the time and expense of being a caregiver didn’t surprise Joseph Briseno, the lack of support for caregivers in 2003 did. While Jay was able to get treatment at then-Walter Reed Army Medical Center in Washington, D.C., his parents were unable to find many caregiver resources they needed at the time.

“It surprised me a lot, especially me being a veteran,” Joseph Briseno says.

Over the years, however, there has been an increase in resources available for these family members. For

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example, Joseph Briseno now is able to enjoy certain benefits — from moral support he receives from the Wounded Warrior Project when he takes Jay to doctor’s appointments to money for personal care aides from the VA’s Veteran-Directed Home and Community Based Services Program, which provides funding that allows caregivers to have more control over their loved one’s long term care services.

Available support for caregivers

In the years since Jay was injured in Iraq, the VA has paid more attention to the needs of those caring for wounded warriors; as a result, the agency offers a number of benefits to ensure veterans and caregivers alike receive the support they need.

“Taking care of our nation’s veterans is the VA’s highest priority, and we know that being the caregiver of a veteran can be a difficult job,” says national VA spokesperson Gina Jackson. “We want people to know that as they

care for the veteran they love, the VA offers a number of services that can provide caregivers with the type of support that’s right for them.”

VA services to these military families include benefits such as:

- the Caregiver Support Line, (855) 260-3274, which enables family caretakers to speak to licensed professionals when they need information about the services they can receive or a sympathetic ear to voice their concerns;

- Caregiver Support Coordinators, licensed health care professionals who are available to help families gain access to the resources they need to care for their loved one; and

- respite care, which allows families to receive up to 30 days of caregiving services a year so caregivers can take a break from their responsibilities to refresh and recharge.

Unaddressed needs

While there are some benefits available to family caregivers, their needs

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still largely are unaddressed and unknown. This lack of support is something former North Carolina Sen. Elizabeth Dole witnessed firsthand when her husband, former Kansas Sen. Bob Dole, was hospitalized for an extended period of time at Walter Reed about 3½ years ago.

“While I was going back and forth to Walter Reed, as I became a caregiver myself, I learned so much about what was happening with the wounded warriors and their family caregivers, and it was an incredible thing for me to see what they were going through — and this was while they were still hospitalized before going home,” Dole says. “It becomes much more challenging once you’re a caregiver in the home and possibly the only person who is knowledgeable, and who is trusted, and who is available to provide care 24/7.”

In addition to the challenges caregivers face, Dole observes the organizations willing to provide support and services also face significant challeng-

es because there is no comprehensive research accounting for the unique and specific needs of military and veteran caregivers. As a result, countless organizations have expressed an interest in the empirical data outlining the needs of caregivers so they can use this information as a roadmap for developing their own plans to address the gaps in services.

Speaking with caregivers, as well as with the organizations that wish to support them, made it clear to Dole more information about the plight of military family caregivers is essential to help them. This ignited a passion in her that led to the creation of The Elizabeth Dole Foundation, which is dedicated to raising awareness about military family caregivers and empowering organizations that want to support them.

To that end, the foundation commissioned a comprehensive, evidence-based study from RAND Corp. to find out what military and veteran caregivers need, what resources are

currently available to them, and how effective those resources are in meeting the needs of these families. In addition, RAND researchers will provide a gap analysis and use the data they collect to make recommendations on how best to serve military caregivers — which Dole believes will be a cornerstone for a national strategy addressing the concerns of wounded warriors and their caretakers.

“This is a societal problem, and there are, as I see it, no comprehensive solutions to these enormous challenges without a national response,” says Dole. “We’re working hard to bring together the public, private, nonprofit, and faith communities around this growing national crisis, as it will take all of us working together to truly make a difference for these families.”

Challenges caregivers face

The final RAND study will be unveiled as part of the Elizabeth Dole Foundation’s National Military and Veteran Caregivers Week, March 24-30, but preliminary findings from the first phase already have outlined a number of challenges to be addressed, including

- The severity of the injuries. Unlike other family caregivers, military caregivers often are taking care of loved ones suffering from multiple injuries and illnesses, which means they need unique and specialized assistance that might be required around-the-clock for years, even decades. Often veterans also are battling unseen wounds of war, so caregivers have to deal with the ramifications of PTSD and traumatic brain injury in addition to their loved one’s physical injuries.

- The complexity of receiving benefits. Many caregivers are not aware of what benefits are available to their family. And when they do know what

assistance they can receive, they often are overwhelmed by the numerous, complicated health care systems they must navigate through to receive help.

■ **The legal and financial matters.** Military caregivers often are required to make decisions about intricate legal and financial matters that can have lasting implications for the whole family. In many cases, caregivers are relatively young, and they are forced to confront issues with which they have little or no experience.

■ **The health consequences of caregiving.** Military family caregivers often are taking care of their loved one on a full-time basis, with few chances for respite; the physical and emotional demands on these caregivers sometimes can lead to the caregivers becoming ill. Studies indicate around 16 to 18 percent of caregivers experience a decline in their own health after taking on the caregiving role, and between 40 and 70 percent of them develop depression.

Heavy toll on relationships

When Rachel O'Hern's husband was injured in Afghanistan about three years ago, losing both of his legs and his right hand as a result, their marriage changed — and they both knew it. She had to learn to relate to him as an injured soldier, and he had to learn to accept what happened to him on the battlefield, which made for a difficult transition for the couple.

“When he got hurt, he went from being such a strong, independent guy to not being able to feed him-

self — and that's a tough emotional transition for everybody,” she says. “I wasn't used to having to help with all that stuff, and he sure wasn't used to having to ask for, or accept, that level of assistance, so it was really hard.”

Capt. Larkin O'Hern is now back on the job, assigned to the Army's Office of the Chief Legislative Liaison. He drives a car and does laundry, and Rachel O'Hern describes her life as “reasonably normal.”

When Army Maj. Kevin Polosky's wife, also a soldier, developed autoimmune disorders after being injured in Afghanistan in 2008, he went through a similar struggle with the changes in his wife and in his marriage.

“The biggest thing I've learned is that you have to come to grips with the fact that your spouse is different. It sounds very easy, but it's not easy to do at all,” he says. “I tell people all the time that I would get really angry at my wife for getting hurt, which is completely selfish. You don't even know why you're doing it, but you're just mad because you had this life planned together, and now you can't do it. And here's this person I fell in love with, and we shared all these things in common, and now we can't do any of those things anymore.”

According to research psychologist Dr. Allison Holmes of the Center for the Study of Traumatic Stress (CSTS), these kinds of challenges are common among family caregivers: Not only are they coping with the physical, psychological, and financial changes that have taken place when

caring for their wounded veterans, they also experience significant relationship changes. And the effects don't end with the marriage, says Holmes, as children in the home also feel the transition.

“Children are definitely facing a lot of challenges, whether it's in school, or emotionally, or getting along with peers,” Holmes says.

Many of the stressors children experience are precipitated by changing roles within the family. In some cases, older children might take on a parenting-type role, caring for their younger siblings to free up their caregiving parent's time to focus on the injured veteran.

To gain more of an understanding of the effects caregiving can have on an entire family dynamic, CSTS currently is conducting a study called Families OverComing Under Stress-Combat Injuries, or FOCUS-CI. In this study, CSTS researchers will follow military caregivers for two years to determine areas where families face the biggest challenges after a combat injury, as well as the resources available to them and the effectiveness of those resources.

With more research providing greater intelligence about the impact of caregiving on military families, resources can be directed more effectively to offer long-term support to those whose lives have been permanently changed as a result of a family member's military service.

“All of a sudden, I had a plan for my life that got completely out of whack because of my wife's injury,” Polosky says, “and until I dealt with that personally and understood how it changed my life — and that's not a bad thing — it was a struggle.” **MO**

— **Kenya McCullum** is a freelance writer based in California. Her last feature article for *Military Officer* was “Simply Fit,” January 2014.

Help Is on the Way

MOAA will release *Tips for Lifelong Caregiving*, an online guide for caregivers of wounded, ill, and injured servicemembers, later this year. An Elizabeth Dole Foundation Innovation Grant helped fund the project; USAA, VetsFirst, and the American Bar Association are sharing their expertise, while Fig Leaf Software and Google will provide digital support services.