

# AMERICA'S UNSUNG HEROES

Challenges and inequities facing  
America's veteran caregivers



Profiles of America's veteran caregivers—who they are, what they do  
and how we can give them the support they need and deserve.



**FULFILLING OUR PROMISES**  
TO THE MEN AND WOMEN WHO SERVED

# Introduction



*Garry F. Augustine*

**Garry Augustine**

Executive Director,  
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In 1970, I was severely injured in a land mine explosion while on a combat patrol in the Batangan Peninsula in South Vietnam. I spent 18 months recovering at Walter Reed Army Hospital and another six months at the Cleveland VA Medical Center where I underwent multiple surgeries, extensive treatments and physical therapy before I was able to return home. There I was, fortunate to have a family who provided me the support and assistance I needed to continue my recovery. Despite the severity of my injuries, I count myself fortunate that I was able to live a rich and fulfilling life.

But some of the men I served with returned home with wounds far worse than mine. Over the years I have met many men and women who lost limbs, suffered extreme burns, were rendered blind, developed serious illness or experienced some other life-altering impairment as a result of their military service. In the most severe cases, these disabilities necessitated the use of a full-time caregiver to tend to their basic everyday needs.

In a single instant, their lives were changed forever. But so, too, were the lives of the spouses, parents and even children who selflessly stepped in to care for these men and women.

Family caregivers sacrifice so much of themselves in order to give their loved ones the highest quality of life possible. Yet the American public is largely unaware of who these caregivers are, what role they play in a veteran's life and the unique obstacles they face.

This report and DAV's new veteran caregiver survey were commissioned to answer those questions. Our goal is to shed light on the challenges veteran caregivers face, including some inequities in how the federal government treats different groups of caregivers. For instance, current policy stipulates that only veterans injured on or after Sept. 11, 2001 are eligible for the full package of caregiver supports offered through the Department of Veterans Affairs.

DAV has been leading the charge to right this injustice. We are grateful that so many of our post-9/11 veterans and caregivers are receiving the assistance they need. We know from their feedback that the support they get—training and education, financial stipends, health insurance and respite care—makes an enormous difference in their ability to effectively manage their caregiving responsibilities and still maintain their own health and well-being.

It is our hope that Congress and the administration will enact legislation that ensures all severely disabled veterans—no matter when they served—have equal access to all of these life-changing benefits. Family caregivers not only enhance the quality of life disabled veterans experience but also save the government significantly in long-term health care costs. Expanding VA's caregiver support program is not just the right thing to do, but the smart thing to do as well.

As a nation, we have a sacred obligation to care for America's veterans. For the most severely disabled, that also means ensuring that their family caregivers have the tools and resources they need to continue performing the many tasks required of them.

It's time we thank and honor these unsung American heroes properly by giving them the full measure of recognition and support they deserve.

# Contents

Who are veteran caregivers	2
<b>PROFILE:</b> Dave and Yvonne Riley	6
The impact of caregiving	7
<b>PROFILE:</b> Mary Ann Keckler	11
<b>PROFILE:</b> Raymond and Pat Dempsey	12
Existing caregiver supports	13
<b>PROFILE:</b> Alexis and Jason Courneen	20
Recommendations to support caregivers	21
<b>PROFILE:</b> Dennis and Donna Joyner	28
Final word	29
Resources	30
DAV Veteran Family Caregiver Survey	31





## Who are veteran caregivers

Informal, unpaid caregivers are tireless individuals—usually family members—who address the many needs of people with serious injuries or illnesses who are medically stable enough to live outside of an institution but lack the strength, functional capability or cognitive skills to care for themselves on an ongoing basis. Individuals with caregiving needs are often unable to perform basic activities of daily living (ADLs) such as bathing, dressing or toileting or to manage medical tasks such as taking medications or coordinating medically necessary care.

People with injuries such as traumatic brain injuries or mental health diagnoses whose functioning is impaired or overwhelmed often require assistance with instrumental activities of daily living (IADLs) such as managing money, housekeeping, preparing meals, shopping and coping during stressful events. These individuals may have issues such as impaired interpersonal skills, lack of judgment, inability to regulate emotions such as anger, impulsivity and inability to focus. Individuals with behavioral health issues are more likely to have co-morbidities, such as substance use disorders, that make them even more prone to job loss and unemployment, poor personal relationships, accidents, engagement in risky behaviors, homelessness and even criminal activity. While some individuals may be able to handle personal hygiene and care needs, they often require close supervision to ensure they are not a threat to themselves or others.

For millions of veterans who have suffered injury or illness in service to our nation, a family member or friend often plays the role of caregivers, occasionally for some and on a full-time basis for others. Some Research exists on caregiving in general, as well as some specifically looking at military veteran caregivers, though primarily for veterans injured on or after Sept. 11, 2001.

To better understand veteran caregivers of all eras, DAV conducted a qualitative online survey of self-identified veterans and caregivers. The results of the DAV survey, which include 1,833 validated responses, should be viewed as a deeper look at the challenges all veteran caregivers face, as well as the support they receive and could use to help care for their loved ones. By comparing and combining our findings with other surveys and research on caregivers, we hope to provide a clearer picture of the lives of veteran caregivers in order to guide critical public policy changes in the coming years.

According to a 2015 study by the National Alliance for Caregiving (NAC) and the AARP, 43.5 million Americans—about 18 percent of the adult population—were involved in caregiving for a family member with a disability or illness in the past year. Of those caregivers, 85 percent are relatives of the recipient. Most of those individuals (80 percent) were most likely to care for one other adult, but some have more adults under their care. Sixty percent of the caregiving population is female. The average age is 49 and most work full-time. About half are taking care of parents or parent-in-laws and 10 percent are

taking care of spouses (these individuals tend to devote the most hours of care to their loved ones). About a third of respondents indicated they spent at least 21 hours a week providing care. On average these caregivers assist with one or two ADLs, with four to five IADLs and with medical tasks.

According to the 2014 RAND Military Caregivers Study, there are 5.5 million caregivers taking care of current or former service members. RAND found just under 40 percent of all military caregivers were more than 55 years old, whereas DAV’s survey reported that over 57 percent were older than 55. As these caregivers continue to age they may be less capable of maintaining their caregiving duties, especially those that require lifting their care recipients (e.g., transferring, bathing and some other ADLs). Despite their aggregate involvement in the workforce, about 18 percent of caregivers come from households with incomes less than 138 percent of the federal poverty level (12 percent more are from households with incomes less than 250 percent of the federal poverty level).

Of the 5.5 million caregivers taking care of current or former service members, the majority (about 80 percent or 4.4 million) provide assistance to veterans from pre-9/11 eras. The remaining 1.1 million (20 percent of military caregivers) who are providing care to veterans of the post-9/11 era generally take care of younger, more able-bodied veterans with behavioral health concerns. The DAV survey had virtually identical results: 80.9 percent were pre-9/11 veterans and 19.1 percent were post-9/11 veterans. RAND found that most military caregivers are women (59 percent)—but, unlike their civilian counterparts they

split between taking care of parents (30 percent military versus 36 percent civilian) and spouses or partners (24 percent military v. 16 percent civilian).  
A 2010 study of the National Alliance of Caregiving and United Health Foundation (NAC Study) found that military caregivers tend to provide care for longer periods of time (30 percent for at least a decade) compared to other caregivers (15 percent for at least a decade).

“In my present caregiver role, I’m three people—the full-time worker, the wife and the ‘husband.’ I work full time and worry full time.”  
—Cori Ferguson  
DAV Veteran Family Caregiver Survey

Similarly, the DAV survey found 38.7 percent of the caregivers had been providing care for 10 or more years, 13.3 percent for 20 or more years, 5.3 percent for 30 or more years and 2.6 percent for over 40 years.  
According to the RAND study, there are key role differences among military caregivers caring for veterans who are ill or injured during military service. Caregivers of younger post-9/11 veterans are more likely to be employed (63 versus 47 percent), be younger (37 percent are younger than 30 years old versus 11 percent) and are more likely to be addressing a behavioral health condition (64 versus 36 percent) than other military caregivers.

Age of Caregivers		Years of Caregiving	
Average age	56	Average years	9.8
Pre-9/11	60.9%	Pre-9/11	10.5%
Post-9/11	43.1%	Post-9/11	6.8%
60 years or older	47.9%	More than 10 years	38.7%
70 years or older	16.5%	More than 20 years	13.3%
80 years or older	2.5%	More than 30 years	5.3%
		More than 40 years	2.6%

Fewer than half say they have important support networks (47 versus 71 percent of other military caregivers) that assist them with relief from the psychological and physical demands of caregiving. Importantly, almost twice as many (58 percent) of the veterans for whom they are providing care have service-connected conditions as those receiving care from other eras (30 percent).

Caregivers of pre-9/11 veterans perform more activities of daily living and instrumental daily living skills than post-9/11 and 46 percent of pre-9/11 military caregivers are over the age of 55 compared to 14 percent of post-9/11 caregivers. Post-9/11 veterans however, seem to require much more assistance from their caregiver with coping skills and memory than other care recipients and a similar amount of assistance with managing paperwork.

The DAV survey found that the most common assistance provided by family caregivers was help with shopping and home maintenance (84 percent), preparing and serving

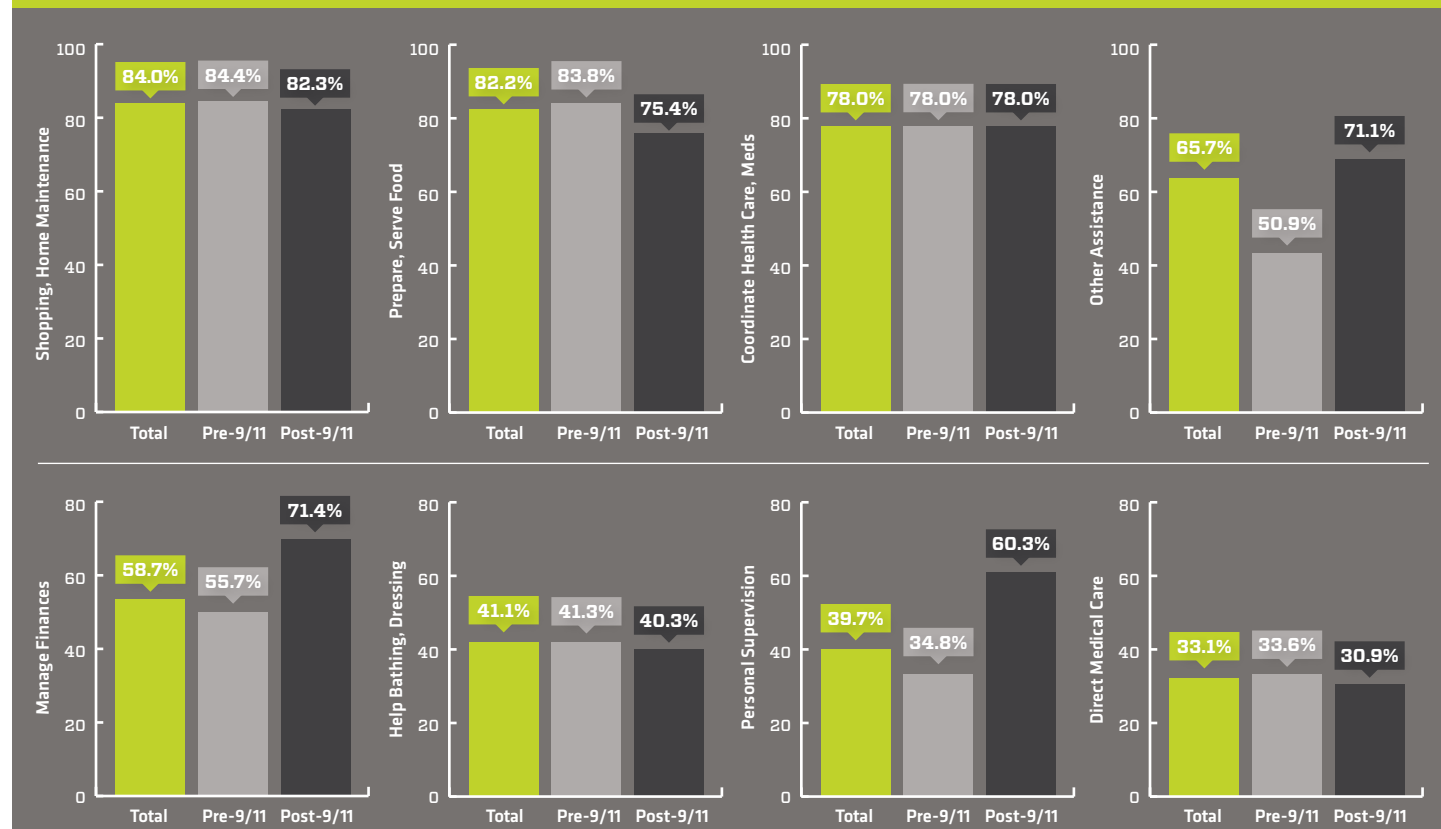
meals (82 percent) and coordinating health care services and medications, including transportation to appointments (78 percent). Other assistance included help managing money and finances (58.7 percent); helping with bathing and dressing (41.1 percent); providing supervision or protection due to neurological or mental disorders, such as PTSD and traumatic brain injury (TBI) (39.7 percent); and providing direct medical care or treatments (33.1 percent).

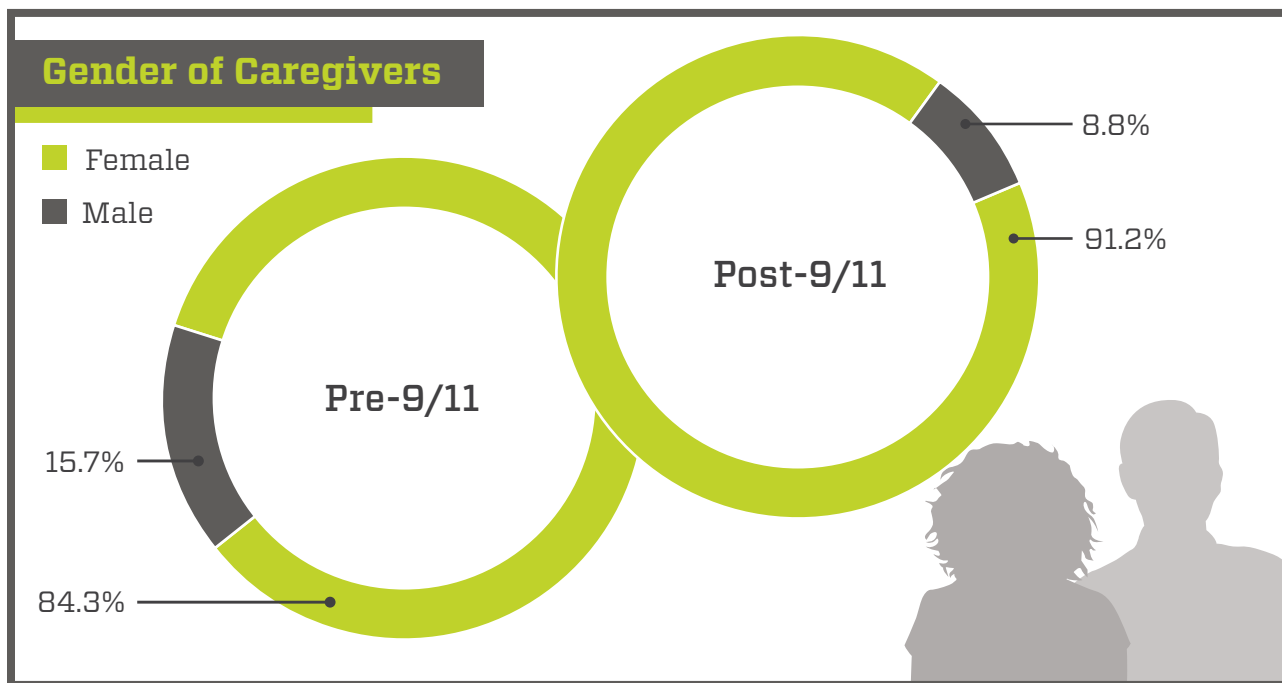
Illustrative of the RAND survey findings, post-9/11 veteran caregivers in the DAV survey were particularly more likely to help with finances compared to pre-9/11 veteran caregivers (71.4 versus 55.7 percent) and to provide supervision (60.3 versus 34.8 percent). These differences likely are a reflection of the greater incidence of PTSD and TBI among post-9/11 veterans.

The NAC study highlights other important aspects of the military caregiver population that suggest their experience with caregiving is different than that of

## Caregiver Services Provided

What types of care or assistance are provided by the caregiver to the veteran?





civilian caregivers. The NAC study found that although 20 percent of military caregivers provide more than 80 hours of care a week and 69 percent provided more than 20 hours a week, only 58 percent received help from other unpaid caregivers, only 33 percent from paid caregivers and only 15 percent reported using respite care. The DAV survey similarly found that 17.6 percent of family caregivers provided more than 80 hours of care per week and 77.1 percent provided more than 20 hours per week. In addition, 12.3 percent of caregivers indicated that they provided more than 112 hours of care per week, which is about 16 hours per day, seven days per week. DAV found that 5 out of 6 caregivers provided care seven days a week.

The DAV survey also found that approximately one of every three veterans with family caregivers also had children living at home; 20 percent had children younger than 18 living with them. As expected this was particularly post-9/11 veterans, of whom 67 percent had children at home, including just over a third of the post-9/11 households (34.3 percent) who had children under 12 years old. In contrast, the RAND survey estimates about 20 percent of pre-9/11 military caregivers and 39 percent of post-9/11 caregivers reported having a child under the age of 18 who lived with them. Although military caregivers in

the RAND study indicated providing care benefited their child and family relations, a sizable minority of post-9/11 caregivers indicated that providing care placed a burden upon their family life.

The RAND study found that private sector agencies are available to address the needs of caregivers for support, providing a helping hand (loans, housing stipends, transportation), education and training and wellness programs to name a few. It is unsurprising that post-9/11 veteran caregivers are more likely to use these sources than other military caregivers given that the types of needs their care recipients have are different than those that would make them eligible for significant support from the VA caregiver assistance program, Medicaid or other public programs. Since veterans with more behavioral health conditions often have different needs, their caregivers receive less assistance than those with more physical burdens. While most post-9/11 caregivers do use the VA for support (73 percent), they are more reliant upon friends and family (92 percent) and almost equally reliant upon places of worship (66 percent) and associations offering military caregiver support (65 percent). They are also more likely than caregivers for veterans of other eras to seek support from state and local government and private associations and caregiver groups.



## DAVE AND YVONNE RILEY

Like many husbands, each day for Dave Riley begins and ends with his wife—Yvonne. But for the Army and Coast Guard veteran, it's only because of his wife that he is able to get out of bed every morning and rest comfortably at night.

"Usually I wake him up, get his shirt on and put his arms on," said Yvonne, who has served as Dave's primary caregiver since the event that took all four of his limbs two decades ago. "I brush his teeth, shave him and comb his hair, get him something to eat and get his legs on and he's all set for the day."

In 1997, Dave contracted a rare bacterial infection during his service in the Coast Guard, resulting in the loss of his arms and legs as well as several of his internal organs. Without any formal training, Yvonne was instantly plunged into the deep end of caregiving for her critically injured husband—from wound care and prescription management to personal hygiene and dressing.

"She allows me to get up, get dressed, get all my prosthetics on and walk among the people like an equal," said Dave.

In addition to providing round-the-clock care for her husband, managing all the household tasks and chores falls to Yvonne as well.

"It probably will get a lot harder as he gets older, but we'll have to deal with that one day at a time when we get there."

—Yvonne Riley

"She takes a lot of that load for me. But as we get older I can see it getting nothing but harder," said Dave. "She's probably aged a lot more than me because there's so much that she has to do and has to worry about."

Caregiving is as much a physical job as it is an emotional one, often requiring a great deal of lifting and providing mobility assistance. Many veterans also experience continued deterioration of their service-connected injuries as well as additional complications as they age.

Despite the considerable progress Dave has made functioning with his prosthetic limbs, he will always rely on Yvonne for many of his basic needs. For caregivers, this often puts their own needs on the back burner and puts them almost entirely on the veteran's schedule.

"You get mad at each other and you're in the middle of a bath, you can't just walk away. You've got to either finish the fight or the bath," Yvonne joked.

Caregiving, Dave notes, is a choice. Yvonne made the decision two decades ago to dedicate herself to her husband's well-being, despite the sacrifices she would have to make. "She chose to take care of me, just about her whole life. She and all caregivers are truly unsung American heroes."

"When I needed her most, she was there for me. And she has continued to support me through every challenge since," said Dave.

It's because of these sacrifices, day in and day out, that Dave believes the nation owes a tremendous debt of gratitude to caregivers.

"As a quadruple amputee, a lot of people ask about and thank me for my service," said Dave. "No one ever stops to thank my wife for the decades of service she's given this country in taking care of me. That's something we need to change."





## The impact of caregiving

**C**aregiver burden is the strain or load borne of caring for an older, chronically ill or disabled family member or other person. It is a multidimensional response to the physical, psychological, emotional, social and financial stressors associated with caring for another person.

Research shows that the caregiver role involves a number of negative consequences impacting employment and financial security, mental and physical health and personal, social and civic connections.

Compared to caregivers nationally, veteran caregivers face unique challenges. For example, about 7 to 8 percent of the general population will have PTSD at some point in their lives and about 8 million adults have PTSD during a given year. About 10 percent of women and 4 percent of men develop PTSD sometime in their lives.

The number of veterans with PTSD varies by service era but is higher than the number within the general

population. About 11 to 20 percent of post-9/11 veterans have PTSD in a given year and about 12 percent of Gulf War veterans have PTSD in a given year. It is estimated that about 30 percent of Vietnam veterans have had PTSD in their lifetime. Another cause of PTSD in the military

can be military sexual trauma (MST).

Among veterans who use VA health care, about 23 percent of women reported sexual assault while in the military and 55 percent of women and 38 percent of men experienced sexual harassment during military service.

According to the VA, veterans suffering from PTSD pose a particular challenge for their family

caregivers. For example, wives of veterans diagnosed with PTSD tend to take on a bigger share of household tasks such as paying bills or housework. They also do more caretaking of children and members of their extended family. The RAND study focus group of military caregivers with children indicated they did not have the time or energy to fulfill their parenting

“I no longer have a life of my own. My husband always has to come first or his life could be in danger of slipping away.”

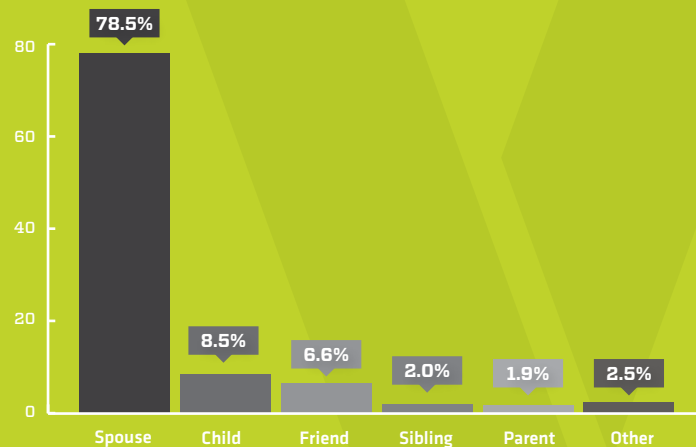
—Linda Alonzo,  
*DAV Veteran Family Caregiver Survey*

responsibilities and were concerned about adverse consequences for their children. Veterans' partners feel that they must take care of the veteran and attend closely to the veteran's problems. They are acutely sensitive to triggers that can exacerbate symptoms of PTSD and work to lessen the consequences, if triggered. In general, the worse the veteran's PTSD symptoms, the more severe the caregiver's burden.

A recent study of female partners of veterans with PTSD found that significant others also suffer from caregiver burden. The partners in this study exhibited high levels of psychological stress with their clinical stress scale scoring above the 90th percentile. In addition to psychological stress, the spouse caregivers fought depression and suicidal ideation.

Caregivers of military veterans have heavy burdens when providing long duration care to veterans with a higher prevalence of mental illness, chronic disease and severe polytraumatic injuries while attempting to participate in the workforce. They consistently experience poorer levels of physical health and are at higher risk for depression. According to the NAC study, over 80 percent

### Relationship of Caregiver to Veteran



of veteran caregivers say they are the primary caregiver compared to only 53 percent of caregivers nationally. While they provide most care, only 11 percent of veteran caregivers share this responsibility equally with another individual and only 7 percent indicate someone else is the primary caregiver.



Veterans caregivers experience a high level of physical strain that appears to be greater than among caregivers generally (40 versus 14 percent, respectively). According to the DAV survey, 82 percent of caregivers had their physical health or fitness negatively impacted, including 41 percent who said it was significantly impacted. Compared to caregivers nationally, veteran caregivers are more likely to remain in their caregiver role longer. For example, they are twice as likely to be in their caregiving role for 10 years or longer than caregivers nationally (30 versus 15 percent). On the other hand, caregivers nationally are more likely to be in their role for under a year compared to caregivers of veterans (38 versus 8 percent).

“We don’t socialize much anymore. His condition has created a type of isolation and loneliness as friends, family and acquaintances don’t understand the reality of what we are dealing with.”

—Carol Fisher  
DAV Veteran Family Caregiver Survey

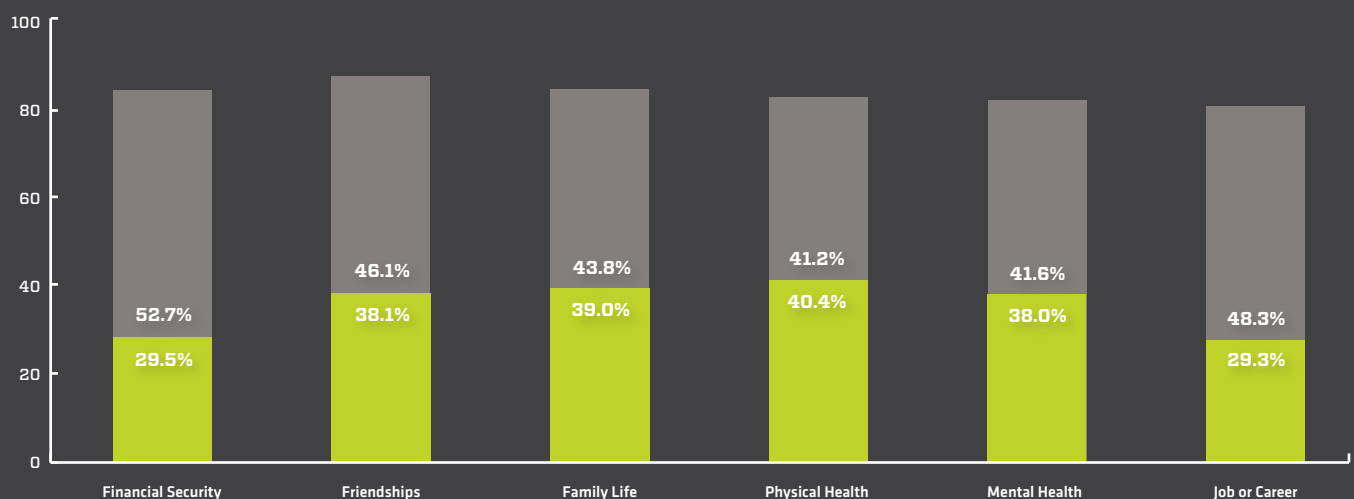
With such time commitments in their caregiver role, it is unsurprising veteran caregivers are often forced to make trade-offs with their careers and financial stability in order to take care of their loved ones. NAC found that 43 percent of veteran caregivers report that they provide more than 40 hours a week of care, the equivalent of a full-time job. Of the 68 percent who were employed while caregiving, 69 percent had to take unpaid time off from work or stop working temporarily, 47 percent say they had to take early retirement or stop working entirely and 62 percent had to cut back the hours in their regular work schedule. Over three-quarters of caregivers in the DAV survey reported that their jobs or careers were limited or negatively impacted due to their caregiving; of those 48.3 percent said their jobs or careers were significantly limited or negatively impacted.

About 18 percent of military caregivers in the RAND study come from households with incomes less than 138 percent of the federal poverty level and 12 percent more from households with income less than 250 percent of the federal poverty level. Civilian caregivers however, are more likely to be from households with incomes below 250 percent of the federal poverty level. In the NAC study, half of the veteran caregivers reported a high degree of financial hardship (50 percent) compared to other

## Sacrifices of Caregivers

■ Somewhat ■ Significantly

Thinking about all the time, effort and sacrifices made by the family caregiver, do you think that may have limited or negatively impacted other aspects of the caregiver’s life, and how significant were those impacts?





“I am the sole provider of his personal and physical needs, which I consider to be my job. But I am almost 84 years old and the daily grind becomes more difficult all of the time.”

—Soon Beetz, DAV Veteran Family Caregiver Survey

caregivers nationwide (13 percent). DAV found that 82 percent of caregivers reported that their financial security was negatively impacted, including 52.7 percent who said it “significantly” hurt their finances. With such financial constraints, caregivers may not be able to afford to pay for supplemental help.

Caring for a veteran with a service-related condition has widespread impacts on the caregiver’s health. According to the NAC study, nearly 90 percent reported increased stress or anxiety and nearly 80 percent reported sleep deprivation. The DAV survey found about 80 percent of caregivers reported that their mental health and well-being were negatively impacted. Because of their devotion, veteran caregivers forgo self-care activities such as keeping their own medical appointments, exercising, eating healthy, attending

social events and pursuing personal interests. These health behaviors decline for more than 60 percent of caregivers. Similar proportions have weight gain/loss or experience depression. Veteran caregivers in the NAC study also said they are twice as likely to be in a high-burden caregiving role and to consider their situation highly stressful (68 versus 31 percent) and have a higher degree of physical strain associated with their role than the general caregiving population (40 versus 14 percent).

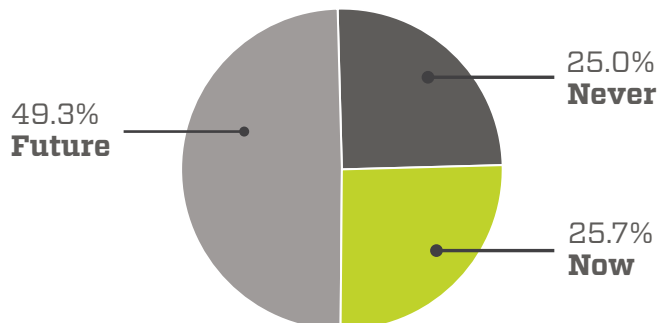
Despite the sacrifices, veteran caregivers are overwhelmingly proud of the service they provide to their loved one. Ninety-four percent feel proud of the support they provide; 78 percent feel a sense of reward from having gained knowledge and skills through caregiving; and 67 percent find caregiving to be fulfilling.

A significant majority (72 percent) of veteran

caregivers also feel isolated, likely due to the perceived lack of understanding by others and the decreased time spent with friends and family. The DAV survey found that over 84 percent of veteran caregivers saw their friendships and social relationships negatively impacted. Almost the same number (82.8 percent) also believed that caregiving negatively impacted their family life and relationships with nearly 44 percent reporting a significant impact. Because of the prevalence of mental and behavioral conditions in the veteran population, more than half (56 percent) of veteran caregivers hesitate to take the veteran anywhere because they are afraid of what might happen, a feeling that can compound one’s sense of isolation.

### Without a caregiver, the veteran would be institutionalized

In your opinion, if there was no family caregiver providing the disabled veteran with care and support, would the veteran need to be placed into institutional care, such as a skilled nursing or assisted living facility, either now or in the future?





## MARY ANN KECKLER

**R**obert Keckler was a young man stationed in Germany in 1987 when he became paralyzed from the neck down after a swimming accident. His mother, Mary Ann, became his full-time caregiver once he was well enough to leave the hospital overseas.

Mary Ann—a veteran herself—left her career to care for Robert. All the things a mother does for her child, Mary Ann found herself doing full time for her adult son. Twenty-four hours a day, seven days a week—her life became solely focused on caring for her son who served his country.

Mary Ann received no assistance such as respite or stipend from the government for all that she sacrificed for her son. She cared for him and helped him to find joy in life, like his love of computers. She made her life revolve around the love and the care she had for her severely injured son until his passing in 2015.

“When you’re taking care of someone who is critically wounded, you do not have time for yourself,” said Mary Ann. “It’s all about them, not about you.”

Family members who provide care to individuals with chronic or disabling conditions are themselves at risk. Emotional, mental and physical health problems arise from complex caregiving situations and the strains of caring for their loved ones.

“The American people do not realize what it takes to be a caregiver,” Mary Ann said. “You have to be there

constantly, up day and night. As a caregiver, you don’t have a life. Your life is completely taken away from you to help somebody who has served this country.”

High rates of depressive symptoms and mental health problems among caregivers, compounded with the physical strain of caring for someone who cannot perform activities such as bathing, grooming and other

personal care activities, put many caregivers at serious risk for poor physical health outcomes. The impact of providing care can lead to increased health care needs for the caregiver.

About two-thirds of the population of caregivers are women and according to the American Journal of Public Health, report higher levels of depressive and anxiety symptoms and lower levels of

subjective well-being, life satisfaction and physical health than male caregivers.

Mary Ann believes any sort of assistance that could provide caregivers some sort of respite from their day-to-day responsibilities could make all the difference in the life of a caregiver.

“Respite to the caregiver is everything,” said Mary Ann. “It gives [caregivers] a break to be able to do something for themselves. Even if they don’t even leave the house or if they just go to a movie, if they can relax and take time for themselves and think about their own needs, that’s what respite would mean for them.”

“The American people do not realize what it takes to be a caregiver. ... As a caregiver, you don’t have a life. Your life is completely taken away from you to help somebody who has served this country.”

—Mary Ann Keckler

## RAYMOND AND PAT DEMPSEY

**T**ake a quick look at Air Force veteran Raymond “Ray” Dempsey and you may not be able to tell he suffered a spinal cord injury while serving on a nuclear, biological and chemical team during Vietnam. But his injuries resulted in the loss of feeling in his extremities, leaving him in need of a caregiver for the rest of his life.

Pat Dempsey—Ray’s wife—has been his caregiver for decades so he can live a high-quality life at their home, all without any support from the government.

“I’m so afraid I’m going to have a problem myself,” Pat said. “Once the caregiver is injured, we’re in big trouble.”

One of the many effects of caregiving can be the feeling of isolation. Often, caregivers are on the job 24 hours a day, seven days a week. Add that up over a few decades and the caregiver often misses out on common social relationships or feelings of individuality. Statistics reveal that between 40 and 70 percent of veteran caregivers experience clinical symptoms of depression, which can be associated with the caregiving experience.

“There are so many things my wife would like to do,” said Ray. “Activities with the neighbors or in the community, but she has to cancel some of those things. She doesn’t go because she has to take care of me.”

“I can’t feel with my hands—they’re usually in a fist—and I can’t feel my feet. So my wife is pretty much my hands and feet.”

— Raymond Dempsey

Under the current law, caregivers to post-9/11 veterans are eligible to receive no less than 30 days of respite care a year. Respite care can mean the caregiver takes care of their own well-being while being confident that their veteran is still being well cared for. They are also entitled to receive mental health services and counseling to meet the unique needs of the caregiver. However, veterans injured before Sept. 11, 2001 are not eligible to receive these life-changing resources.

“I think it should be awarded to all veterans from all generations,” said Pat. “Whether you have a spinal cord injury from Vietnam or a spinal cord injury from the Gulf War, you still have that injury. You still need quality care.”

“As we get older, we will need caregivers more and more,” Ray said. “I can’t live day to day without my caregiver. I’m so proud that the government is supporting [the caregiver program] for today’s veterans. But I do believe veterans from all conflicts and wars should have a caregiver. And their caregiver should be eligible for the same benefits and resources.”







What interventions and supports exist? Who are delivering those supports?

## Existing caregiver supports

**W**hile many veterans will recover from severe illnesses and injuries, many others will need a lifetime of support from family caregivers. Despite documented physical, emotional and financial hardships and knowledge of effective interventions against caregiver burden, family caregivers of disabled veterans receive little support from the federal government, compromising their ability to provide care to their loved one. Despite myriad programs in the VA and other federal and state agencies, resources are inadequate, eligibility is restricted and each program has other limitations. Further, there is little or no coordination among the many programs.

### DEPARTMENT OF VETERANS AFFAIRS (VA)

The VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC) is available only to veterans and service members who served after Sept. 11, 2001 and who have permanent, catastrophic injuries, receive outpatient care, and have a designated primary caregiver who provides assistance with at least one basic personal care activities (also called an Activity of Daily Living or ADL). PCAFC is the first and only integrated program that is required to provide a monthly stipend, coverage for travel expenses, access to health coverage, mental health care, peer counseling, respite care, and basic and injury-specific caregiver training.

For veteran caregivers severely ill and injured before Sept. 11, 2001, VA offers caregiver support through programs that are primarily within the VA's

office of geriatrics and extended care because of this population's need for long-term services and supports, including family caregivers. In 2016, of all veterans enrolled in the VA health care system 48 percent were aged 65 and over, with Vietnam-era veterans being the largest cohort of veterans and the cohort now reaching advanced age. Of all VA long-term services and supports, the following types of home- and community-based care are those having a more direct impact in supporting family caregivers, which includes: Respite services provided through other services such as adult day care, homemaker and home health aide and skilled home care; home-based primary care; case management and coordination; transportation services; general caregiver education; and veteran-directed home and community based services.

### RESPITE CARE

Intended to give family caregivers a short-term break from their role as caregivers, respite care provides veterans needed skilled services and case management, as well as help with activities of daily living. Respite services can help relieve stress and isolation for family caregivers by allowing them to take time to run errands or go out of town for a few days without worrying about the veteran being left alone at home.

Respite care is provided in an inpatient (VA medical center, nursing home) setting, outpatient (adult day care) or in-home setting (Homemaker and Home Health Aide Care and Skilled Home Health Care).

## ADULT DAY HEALTH CARE (ADHC)

Designed as an outpatient day program, ADHC can serve as respite for family caregivers. There are three basic models of ADHC: social, medical or combined. Social models tend to focus on socialization and prevention services, while medical models include skilled assessment, treatment and work toward established rehabilitation goals. Combined models cover all areas. Clear distinction among these models has blurred as they have evolved into a dynamic, comprehensive model of care.

A limited number of VA facilities offer onsite Adult Day Health Care targeted toward veterans with cognitive impairments that need supervision and veterans who would otherwise need nursing home care without assistance with personal care and other daily activities for independent living. In addition, there are a small number of State Veterans Homes that offer medical ADHC under a partnership between the VA and state governments. Pending legislation supporting this partnership may encourage growth of ADHC in State Veterans Homes.

## HOMEMAKER AND HOME HEALTH CARE AIDE

Purchased using contracts by the VA from community agencies, help with daily tasks is provided by trained homemakers or home health aides and supervision by a registered nurse. Homemaker and home health aides work for an organization that has a contract with the VA and can be used as a part of an alternative to nursing home care and as a way to provide respite to family caregivers.

A VA provider assesses the need for the service and places an order. A VA coordinator contacts the veteran to discuss his or her needs, determines the amount of care to be provided based on clinical need and makes a referral to a community home health agency.

## SKILLED HOME CARE

Primarily purchased from community providers, skilled home care is provided by qualified personnel for a limited time with the goal of rehabilitation or restoring—not necessarily maintaining—health status. In-home services include physical, occupational or speech therapy, intravenous therapy and wound care. The VA generally uses its provider agreement authority to purchase skilled home care from Medicare-certified home care agencies. Family caregivers are able to take a break from their

caregiving roles or are able to receive additional or refresher training on such things as wound care or on home ventilators.

A VA physician determines that a veteran needs the skilled care and then orders it. VA coordinators contact the veteran and arrange the care. The VA monitors the agencies' quality measures at least annually.

## HOME BASED PRIMARY CARE

Eligible veterans receive long-term, comprehensive primary care services in their home coordinated by an interdisciplinary VA health care team. Generally, severely ill and injured veterans who have difficulty leaving their homes, who are unable to cope with receiving care in a clinic setting due to chronic health conditions, need

“The biggest challenge is that caregivers need to be trained in how to advocate for the veteran family member. In my situation, I too am a veteran so I know a lot of the ins and outs of the system. But most folks don't know who or where to turn to for help.”

—Susan Mullins,  
DAV Veteran Family Caregiver Survey

complex care or have recurrent hospitalizations are eligible for Home Based Primary Care.

Led by a VA physician, the Home Based Primary Care team includes, nurse practitioners or physician assistants, nurses, social workers, physical or occupational therapists, mental health providers, pharmacists and dietitians. The team members make separate home visits, develop a care plan that involves the veteran and their family caregiver and provide personalized case management for veterans and necessary training for family caregivers.



## VETERAN-DIRECTED HOME AND COMMUNITY BASED SERVICES

Since its inception in 2008, this program has become available at 68 of 167 VA medical centers and served 1,751 veterans in fiscal year 2016. It is designed to help veterans who are at-risk of nursing home placement when their family caregiver(s) need help, have home care needs that exceed the average number of hours generally available at a VA medical center or have difficulty using a traditional home care agency that allows them to safely reside at home.

Because of its design, veterans have decision-making authority over certain services and take direct responsibility managing the services they need—but they are not alone. All veterans in VD-HCBS are supported by the VD-HCBS VA program coordinator, an options counselor from an Aging and Disability Network agency and a financial management service. The VA program coordinator establishes the veteran's eligibility for the program and provides program orientation to the veteran and his or her family caregiver(s). Once enrolled, the VA medical center authorizes a monthly flexible spending budget based on the veteran's assessed needs. For example, the flexible budget allows veterans in this program to hire family and friends as caregivers to provide the personal care services they need.

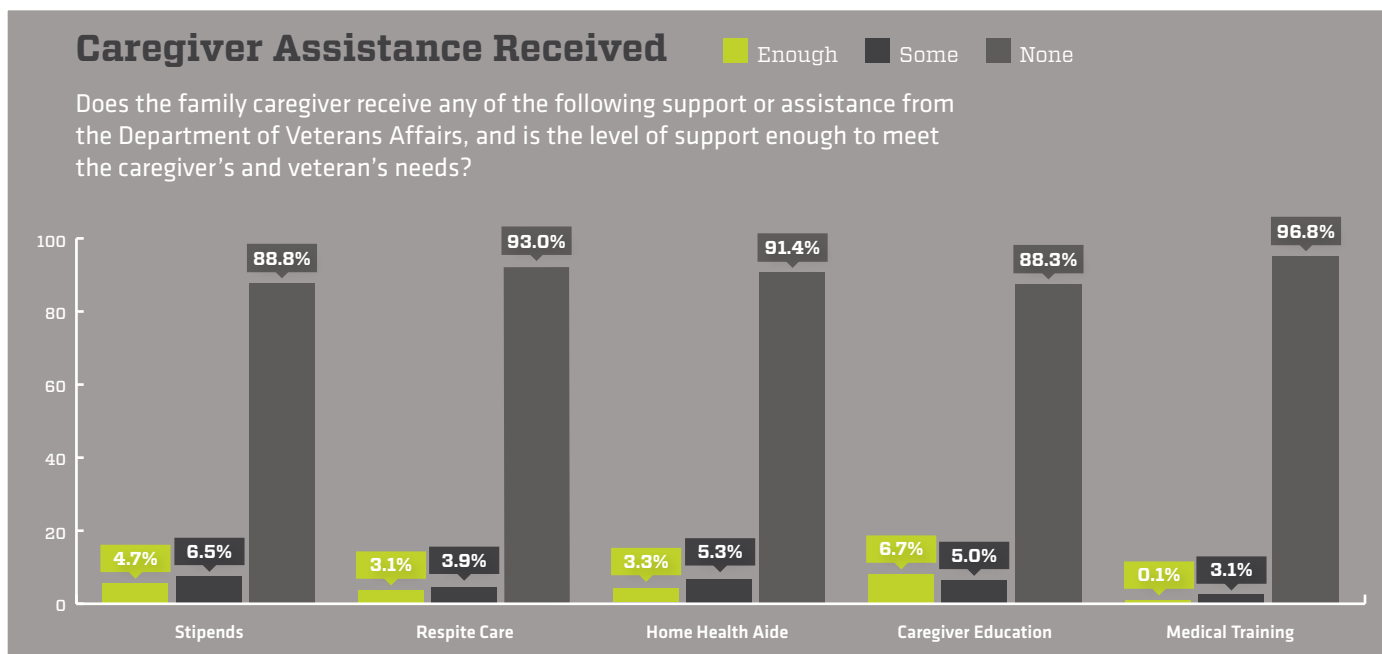
The local Aging and Disability Network agency then works with the veteran to develop a personalized service plan, to find, choose and train workers and to acquire needed goods and services that allow the veteran to live safely and independently at home. The financial management service helps veterans prepare their workers' paychecks, tax returns and other payroll forms and pay for those items consistent with the service plan.

The VA program coordinator oversees quality, veterans' satisfaction and service delivery. For example, the coordinator can help identify other VA benefits to help maximize the veteran's flexible budget to purchase certain items (touch lamps, chair lifts, etc.) that directly affect his or her ability to continue to live independently (touch lamps, chair lifts, etc.).

## DEPARTMENT OF DEFENSE (DoD)

For caregivers of military service members with complex care needs, the DoD offers programs within each military branch. Wounded warrior programs offer patient-advocacy and helping-hand services for caregivers of wounded, ill or injured service members.

According to DoD Instruction 1300.24, a recovery team; wounded ill and injured service member, and family or designated caregiver prepare a patient-centered recovery plan with medical and nonmedical goals for recovery,



rehabilitation and transition. The plan is also prepared with personal and professional goals and the identified services and resources needed to achieve the goals.

A recovery team includes the wounded, ill or injured service member's commander, the wounded, ill or injured service member, a Recovery Care Coordinator or a Federal Recovery Coordinator, a medical care case manager and a nonmedical case manager. The recovery team may also include medical professionals including primary care managers, mental health providers, physical and occupational therapists and others such as physical evaluation board liaison officer (PEBLOs), VA military service coordinators, chaplains and family support program representatives.

The new lead coordinator initiative is intended to help to ease the transition for service members requiring complex care management and their family caregiver(s) as they transition from or within the DoD system of health care and the VA. The lead coordinators role may be filled by various members of the individual's care team, such as the Recovery Care Coordinator, Physical Therapist, nonmedical case manager, etc. The role is to serve as the primary coordinator for the most seriously wounded, ill, injured or disabled service members or veterans. The Lead Coordinator has a master checklist to help guide and assist patients and their family caregivers understand the benefits and services they are entitled to as they go through the recovery and transition process.

The DoD's Special Compensation for Assistance with Activities of Daily Living (SCAADL) benefit provides financial stipends to service members who served after Sept. 11, 2001 and have permanent, catastrophic injuries, are receiving outpatient care and have a designated primary caregiver who provides assistance with at least one ADL.

### **CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)**

Medicare-covered Home Health Agency (HHA) services under Section 1861(m) of the Social Security Act (SSA) include skilled nursing care, home health aide services, and can include caregiver supportive services—teaching and training activities that require skilled nursing personnel to teach the beneficiary's family caregivers how to manage the treatment plan.

**Limitations:** HHA services under 1861(m) would not be provided where a family caregiver is or will be providing services. Homebound status assessment for services is strictly applied (denied due to wandering of patients with severe cognitive impairment). When services are approved by a physician, services provided have been reported to be less than what was ordered and less than what the law allows.

### **NO WRONG DOOR SYSTEM**

This collaborative effort of the Administration for Community Living (ACL), CMS, VA, Area Agencies on Aging, Centers for Independent Living, state Medicaid agencies and state units on aging supports efforts to streamline access to long-term services and supports (LTSS) options for all.

**Limitations:** At state levels, the initiative is in varying degrees of development and is not available across all 50 states.

### **MEDICAID HOME AND COMMUNITY-BASED SERVICES:**

The following Medicaid Waiver Programs that offer non-institutional in-home and community-based care are federally supported state-run programs that include standard services, such as case management, homemaker, home health aide, personal care, adult day health care, habilitation and respite care.

**Limitations:** Families are required to impoverish themselves to qualify for the income and asset test. States serve limited geographic areas, vary in whether services are eligible for nonelderly care recipients, caregivers who are nonfamily members, and caregivers who receive a stipend under self-directed services. Moreover, Medicaid HCBS programs often reduce the hours of care authorized when the beneficiary has a family caregiver. If family caregivers are expected to continue providing support, HCBS programs must assess and address family caregivers' individual needs.

### **MEDICAID SELF-DIRECTED SERVICES**

All state Medicaid programs allow self-direction under a variety of Medicaid home- and community-based service state plan and waiver options, including the Home and Community-Based Services state plan option—1915(i); Community First Choice—1915(k); Self-Directed Personal

Assistance Services state option—1915(j); and Home and Community-Based Services waiver programs—1915(c).

Self-directed means beneficiaries are given the flexibility to select their care providers rather than have Medicaid choose providers on their behalf.

Individuals may choose to participate in either: (1) the traditional agency model, in which a qualified agency hires, pays and trains personal care attendants to provide services to an individual; or (2) the self-directed model, in which the individual directs many or all of their home- and community-based services, to include selecting and managing direct service workers in the provision of services to the beneficiary.

**Limitations:** In 2015, only 43 states with 1915(c) waivers, 24 states with personal care plans, and seven states with home health plans permitted self-direction. Medicaid regulates the amount they can be paid and usually prohibits payment to legal guardians and spouses, but notably does not prohibit payment to the adult children or ex-spouses. Under Self-Directed Personal Assistance Services state option - 1915(j), the beneficiary can hire family members as personal caregivers. Only some states may allow individuals to combine the traditional agency-directed model with self-directed model for the same services, such as using agency-based services during the week with self-directed services on a weekend, or purchasing agency-based services through a self-directed model.

### MEDICAID 1915(C)

This waiver accounts for the largest share of Medicaid HCBS enrollment and expenditures. Under this waiver, states may provide respite care, training and family counseling. Training to caregivers to the extent it is necessary to enable the participant to be cared for outside an institution. Training

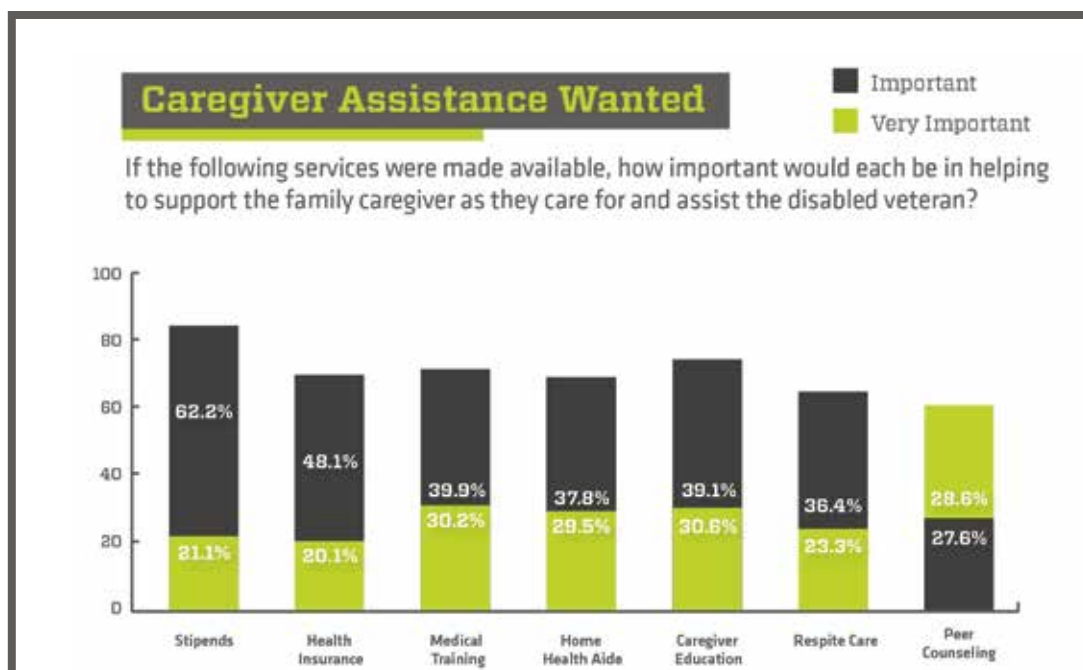
includes instruction about treatment regimens and other services in the treatment plan, such as use of equipment and updates as needed to safely maintain the beneficiary at home. All training for family caregivers must be included in the participant's service plan. Legally responsible relative may also be paid to provide care that is "extraordinary" (e.g., a parent lifting a 1-year-old is ordinary; lifting an 18-year-old is extraordinary). The services provided by the caregiver need to be necessary in order to prevent the beneficiary from being institutionalized.

**Limitations:** In 2015, all states reported using restrictive financial and functional eligibility standards, enrollment limits or waiting lists (more than 640,000 people were on 133 waiver waiting lists, and the average wait time exceeded two years).

### MEDICARE ADVANTAGE PLANS

Medicare Advantage plans can offer respite care and electronic monitoring of beneficiaries as a supplemental benefit. In addition, plans may offer, as an administrative service, caregivers assistance in identifying community-based resources specific to the needs of the beneficiary.

**Limitations:** Medicare Advantage plans are not required to offer respite or electronic monitoring. Some Medicare Advantage Special Needs plans may cover respite care but limit membership with varying criteria.



“My husband is a 100 percent service-connected veteran that cannot read, write or speak. His right arm is paralyzed and right leg weak and he is in a wheelchair and braces. All home care is done by me, all chores are done by me. We just barely pay our bills and I have medical issues, too, but I cannot afford health care.”

—Ute Ross

### THE ADMINISTRATION FOR COMMUNITY LIVING (ACL)

Part of HHS, ACL was created around the fundamental principle that older adults and people with disabilities of all ages should be able to live where they choose, with the people they choose and with the ability to participate fully in their communities. ACL funds support research in innovation as well as for services and supports provided by networks of community-based organizations.

ACL programs that help support and empower those caring for older adults and people with disabilities include:

- The National Family Caregiver Support Program.
- The Lifespan Respite Care Program.
- Native American Caregiver Support Services Program.
- Eldercare Locator.
- University Centers for Excellence in Developmental Disabilities Education (UCEDDs).

### THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM (NFCSP)

Established in 2000 and provides grants to states and territories, to caregivers who provide care and assistance to aging parents caring for adult children with disabilities, to grandparents raising grandchildren, to family caregivers caring for individuals of any age with Alzheimer’s disease or related disorders or to family caregivers of aging adults 60 years or older.

Grant recipients must provide five types of services that work in conjunction with other state and community-based

services to provide a coordinated set of supports:

1. Information to caregivers about available services.
2. Assistance to caregivers in gaining access to services.
3. Individual counseling organization of support groups and caregiver training.
4. Respite care.
5. Supplemental services, on a limited basis.

**Limitations:** There is no requirement Medicare Advantage plans offer respite or electronic monitoring. Some Medicare Advantage Special Needs plans may cover respite care, but limit membership with varying criteria.

### THE LIFESPAN RESPITE CARE PROGRAM

Public Law 109-442, the Lifespan Respite Care Act, was enacted in 2006 and authorized approximately \$288 million over five years to provide grants to individual states to help family caregivers access and coordinate respite care. No other federal program mandates respite as its sole focus, helps ensure quality, accessibility, affordability and choice of respite care, or provides startup funds for respite, training and coordination to address basic issues for family caregivers regardless of age or disability.

Through 2016, eight rounds of grants to established Lifespan Respite Care Programs in 35 states. The exact services and procedures are specific to the individual state though all programs share certain components. These competitive grants are intended to provide a coordinated system of accessible, community-based respite care services (including emergency respite) and are awarded to eligible state agencies working in collaboration with a public or private non-profit state respite coalition or organization to make quality respite available and accessible to family caregivers regardless of age or disability.

**Limitations:** Funding limitations provided grants to only 35 states and the District of Columbia to address known barriers to respite care including short supply of well-trained respite providers, lack of outreach and education about respite (including how to find and choose a service provider), cost, fragmented services, and restricted targeting of services.

### NATIVE AMERICAN CAREGIVER SUPPORT SERVICES PROGRAM (NACSSP)

According to the VA, there were over 150,000 American



Indian and Alaska Native (AIAN) veterans in 2010. AIAN veterans have served in the United States military since the Revolutionary War. This program provides grants to federally-recognized tribal organizations that support American Indians, Alaska Natives and Native Americans in the areas of nutrition, supportive services for older adults and caregiver services. The nutrition and supportive services grants include congregate and home-delivered meals, information and referral, transportation, personal care, chores, health promotion and disease prevention and other supportive services.

The caregiver services grants include assisting families in caring for older relatives with chronic illness or disability and grandparents caring for grandchildren. There are other necessary services provided by ACL grants so people have meaningful support to help them live independently in their communities.

**Limitations:** Advocates for this program voice concern over the funding level of this critical program. Older Americans Act (OAA) Title VI programs rely on a number of funding sources in order to provide a wide variety of services in their communities. All Title VI Organizations receive funding from the Title VI. The most common funding sources after Title VI are, Nutrition Services Incentive Program (NSIP) and Tribal Council funding. Nearly 60 percent of Title VI programs (58.8 percent) reported in 2014 that their funding levels have decreased since 2011 with very few programs reporting an increase.

## THE ELDERCARE LOCATOR

Launched in 1991, the Eldercare Locator was established. Funded by the Administration on Aging, a component of the Administration for Community Living and is administered by the National Association of Area Agencies on Aging. It is the only national information and referral resource to provide support across the spectrum of issues for older adults and their caregivers.

Through its national call center (800-677-1116), which operates five days a week from 9:00 a.m. to 8:00 p.m. Eastern time and website ([www.eldercare.gov](http://www.eldercare.gov)), the Eldercare Locator serves as a trusted gateway and instant connection to resources that enable older people to live independently in their communities and offers support for caregivers. In 2014, the Eldercare Locator's call, online chat and email volume received over 270,000 requests for

assistance from all fifty states, the District of Columbia and most U.S. territories.

Certified Information Specialists refer the majority of inquiries to the 622 Area Agencies on Aging and 256 Title VI aging programs that provide vital services and supports in virtually every community in America; referrals are also made to federal/state agencies and nonprofits.

**Limitations:** The Eldercare Locator work volume has been increasing; however, family caregivers referred to community resources experience challenges in having their needs met.

## THE UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH AND SERVICE (UCEDDS)

These Centers are a nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions and advancing research related to the needs of individuals with developmental disabilities, including TBI and their families.

As Administration on Intellectual and Developmental Disabilities (AIDD) program grantees, 68 centers are affiliated with universities throughout the United States and its territories to serve as liaisons between academia and the community.

Centers receive a discretionary grant that is awarded to interdisciplinary education, research and public service units of universities or public or nonprofit entities associated with universities. AIDD funding is used to support the organizational foundation of UCEDDs, which allows the grantees to pursue other sources of support to conduct various activities. UCEDDs leverage funding from a variety of sources, including federal, state and local agencies; private foundations; donations; and fee-for-service earnings. Four core functions frame the UCEDD program:

- Interdisciplinary pre-service preparation and continuing education.
- Research, including basic or applied research, evaluation and public policy analysis.
- Information dissemination.
- Community services, including direct services, training, technical assistance and model demonstrations.

## ALEXIS AND JASON COURNEEN

**A**lexis Courneen, a 19-year-old seaman in 1998, was on her first duty assignment in the Coast Guard when she was struck by a several-ton buoy. The accident crushed the nerves of her right arm, broke her hip and slammed her head into the deck. She was medically evacuated from the ship and put on administrative duty. Over time, it became apparent that Alexis was suffering from short-term memory loss and had trouble concentrating. She was medically discharged from the Coast Guard in 2000.

In 2003, Alexis married Jason, whom she had known since she was 13 years old. She said she told Jason about her accident and that it had affected her abilities to perform everyday tasks.

What Alexis—and Jason—didn't know at the time, was that Alexis had symptoms of TBI. Headaches, memory problems, angry outbursts and blurred vision made it difficult for Alexis to manage mundane tasks on her own. Jason became her caregiver and was often forced to choose between providing for Alexis or going to work.

"I'm our girls' father, her husband, I'm her best friend," said Jason. "Caregiver is way down on the bottom of the list. I recognize that I have that role, I just don't like that word.

'Caregiver' sounds like I'm taking care of her and that's not it. She's taking care of herself the best that she can and I fill in the blanks."

The Courneens are among the many veterans and caregivers who don't qualify under the current law for caregiver benefits such as training,

stipends or respite care. Only because Alexis' injuries occurred before 9/11. But they do make it a priority for their family to be as socially and physically active as possible with volunteer programs and support systems available like adaptive sports clinics for disabled veterans.

"The [adaptive sports clinics] are a big deal because most of the people I consider to be my best friends are here," said Jason. "It's huge for our family because I get to watch Alexis excel at the things she used to do before she got injured."

The support systems and activities available to the Courneen family are essential to their well-being, but are often only possible due to volunteers or sponsored activities.

"There's not a lot of support groups out there," said Jason. "It makes my role as a caregiver a lot easier to know that we have that sense of security that sense of support that sense of help we find at the clinics. And that's huge."

"I told him that if he expected me to be the same person he knew in high school, he would be disappointed."

—Alexis Courneen



# Recommendations to support caregivers

Over time, the need for caregiver services and supports will likely increase as greater numbers of family caregivers and veterans with chronic disabilities age. Polytraumatic conditions for which younger veterans need care (e.g., physical and traumatic brain injury and/or mental health conditions) may change as will the needs of their family caregiver. Adequately supporting caregivers of all eras is a critical and necessary course of action to avoid the much higher costs of providing full-time institutional care to aging disabled veterans. The DAV survey found that approximately half (49.3 percent) of all veterans who rely on caregivers today would need to be placed into a skilled nursing home or assisted living if they no longer had their family caregiver; another quarter (25.7 percent) said the veteran would require institutionalization in the future. These results were consistent for both pre- and post-9/11 veterans who rely on caregivers.

The DAV survey asked caregivers and veterans with caregivers how important various types of caregiver assistance would be to the caregivers and found tremendous needs. Over 83 percent of caregivers indicated that direct financial support, such as the Program of Comprehensive Assistance for Family Caregivers (PCAFC) stipends, would be important or very important; just 4.7 percent said such aid would not be necessary. Almost half (48.1 percent) said that health insurance for the caregiver would be very important, with post-9/11 caregivers indicating a

greater need (59.1 versus 45.4 percent) likely due to greater eligibility for Medicare among the pre-9/11 caregiver population. Overall, caregivers of all eras indicated a significant need for support and assistance to enable them to better fulfill their caregiving responsibilities.

Because existing federal policies and programs failed to adequately recognize the great and many sacrifices family caregivers make to support our nation's heroes, Congress required VA to establish the first and only comprehensive program integrating supports and services tailored to assist family caregivers.

## VA CAREGIVER SUPPORT PROGRAM

In response to meeting the needs of family veteran caregivers severely injured on or after Sept. 11, 2001, Public Law 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010, was signed into law establishing the PCAFC. Prior to this law, existing VA authorities, policies, programs and services caring for severely ill and injured veterans incidentally helped their family caregivers. The law made family veteran caregivers direct recipients of services, expanded eligibility for certain benefits and reoriented existing programs and policies to directly address their needs. PCAFC integrated the administration and delivery services and supports to family caregivers of severely injured in the line of duty on or after Sept. 11, 2001.





Veterans severely injured in the line of duty before Sept. 11, 2001 and veterans severely ill after Sept. 11, 2001 are not eligible to participate in PCAFC. The law did establish a general caregiver support program to offer limited support to family veteran caregivers severely injured before Sept. 11, 2001 or who are otherwise not eligible to participate in PCAFC.

After Public Law 111-163 was enacted, VA established the Caregiver Support Line (1-855-260-3274) staffed by licensed professionals to meet the immediate needs of all family veteran caregivers enrolled in VA for health care and to answer questions about what services they or their veteran may be eligible for. All such family caregivers are also able to access Caregiver Support Coordinators, licensed healthcare professionals primarily social workers, who can support caregivers by matching needs with VA and community services. Locating a Caregiver Support Coordinator can be done through the Caregiver Support Line or a Zip code look-up on VA's Caregiver Support Website ([www.caregiver.va.gov](http://www.caregiver.va.gov)). The Peer Support Mentoring Program was also created to provide guidance and emotional support to combat caregiver isolation.

More than 30,000 caregivers have received services and support through PCAFC, which includes caregiver education and training and can be completed at home with a workbook and DVD, online or in a classroom setting. Topics include 10 core competencies with topics such as caring for oneself as well as the veteran. Disease and injury specific training is also provided such as understanding Post-traumatic Stress Disorder from the caregiver's perspective. To help alleviate financial distress of the caregiver, a monthly stipend is paid directly to designated primary family caregivers. To address the psychological burdens of caregiving such as isolation, depression, anxiety, anger, sleep disturbances, challenges to the personal relationship with the veteran, etc. family caregivers are eligible to receive mental health services.

Respite care, which is generally provided for no more than 30 days per year, under PCAFC is to be age-appropriate and includes in-home respite care of not less than 30 days annually, including 24-hour per day care of the veteran commensurate with the care provided by the family caregiver to permit extended respite.

According to VA, there is lower than expected utilization of respite care in PCAFC. Assumptions range from unavailability of service in the community to entrusting the health and well-being for their veteran to a stranger.

VA is to reimburse family caregivers for travel expenses including lodging and subsistence for the time in which the veteran is traveling to and from a VA facility for care. Family caregivers not eligible for TRICARE or entitled to care through Medicare, Medicaid, employer sponsored health-plan or other such contracts, can enroll in VA's Civilian Health and Medical Program (CHAMPVA)—a

health care benefit program in which VA shares the cost of certain health care services and supplies with eligible beneficiaries. An important benefit under PCAFC is the ongoing support and monitoring of family caregivers and veterans and service members, primarily performed through home visits to ensure caregivers have the requisite training for their particular caregiving needs, resources and support to provide safe and effective care.

"I was a caregiver for my father until his death in October 2011. It was quite difficult at times as my mother was also nearing the end of her life. Managing both of them at the same time I was literally burning the candle at both ends."

—Susan Mullins

Under the general caregiver support program, family caregivers are able to use the Caregiver Support Line and Caregiver Support Coordinators, online and in-person caregiver educational sessions, telehealth and other technologies. In addition, counseling such as consultation, professional counseling, marriage and family counseling, training and mental health services are to be made available, as well as age-appropriate, including 24-hour per day in-home respite care.

Despite the creation of the general caregiver support program, the law and subsequent policies continue to



treat family caregivers under this program as incidental. For example, caregiver counseling under this program is required to be “in connection with the treatment of veterans with certain service-connected disabilities” rather than in connection with their role as family caregivers. In addition, the respite care benefit under this program remains limited by policy. Further, any additional days needed for respite beyond 30 days requires additional administrative and clinical steps. Other limitations under the general caregiver support program include the lack of eligibility for family caregiver travel, lodging and subsistence allowance such as that offered under PCAFC. Finally, according to VA, unlike PCAFC, there is no formal application process for the general caregiver support program and are therefore not tracked nationally.

- **Congress:** Because family caregivers of severely disabled veterans need integrated comprehensive caregiver supports and services offered under PCAFC to remain in their caregiving role, Congress should allow these family caregivers and veterans to participate in PCAFC.

#### PCAFC IMPROVEMENTS NEEDED

Post-9/11 caregivers tend to be younger, are more likely to be a spouse, friend or parent, and are more likely to be employed. They are more likely to care for a veteran who is in receipt of VA disability compensation, or who suffers from a traumatic brain injury or has a behavioral health problem. They are less likely to have a support network and have a higher likelihood of depression.

Due to the prevalence of emotional and behavioral challenges among post-9/11 veterans, their family caregivers tend to provide more assistance in helping their veteran avoid triggers of anxiety, cope with stressful situations or avoid antisocial behavior. However, the eligibility to participate in PCAFC is limited to veterans severely injured (including traumatic brain injury, psychological trauma or other mental disorder) due to military service on or after Sept. 11, 2001—it does not allow family veteran caregivers severely ill due to military service on or after Sept. 11, 2001 to participate.

DoD’s Special Compensation for Assistance with Activities of Daily Living (SCAADL) program covers injuries as well as illnesses. This program helps offset the loss of income by a primary caregiver who provides



non-medical care, support and assistance for the service member who incur a catastrophic injury or illness. Thus, while SCAADL encompasses more conditions than PCAFC, it is not as comprehensive and this incongruity makes transitioning from one program to the other difficult.

According to RAND, post-9/11 veteran caregivers support needs are different than that of pre-9/11 caregivers, who are more likely to use other private and community sources, because the types of needs their care recipients have are different than those that would make them eligible for significant support from the VA’s Caregivers Assistance Program, Medicaid or other public programs.

The DAV survey reveals such differences between caregivers of post-9/11 veterans who provide greater support than caregivers of pre-9/11 veterans on matters such as money and finances (71 versus 56 percent), personal supervision (60 versus 35 percent) and for other types of help and assistance (71 versus 51 percent). The RAND report found similar results with managing finances (61 versus 56 percent) and supervision (75 versus 49 percent).

The DAV survey also found that approximately one of every three veterans with family caregivers also had children living at home; 20 percent had children younger than 18 living with them. As expected this was particularly the case for post-9/11 veterans where 67 percent had children at home, including just over a third of the post-9/11 households (34.3 percent) who had children under 12 years old. However, having children in the same household impacts respite care delivery to the caregiver, particularly if agencies are utilized and do not provide child care while caring for the veteran. When asked in the DAV how important respite care is to survey participants, nearly 60 percent indicated it is important or very important; however, only a small minority (7 percent) receive respite, of which only 3 percent believe they are receiving enough respite, while the vast majority (93 percent) are not receiving any respite whatsoever.

- **Congress:** VA should be authorized to provide caregiver supports under PCAFC that are tailored to the needs of family caregivers, particularly with legal and financial counseling and childcare to be used in conjunction with caregiver respite services.

## IMPROVING VA GENERAL CAREGIVER SUPPORT PROGRAM

VA has streamlined access to information about caregiver resources, supports and services within VA. VA implemented a National Caregiver website to provide education and resources to all family veteran caregivers in an

effort to ensure this type of information is easily accessed.

Yet the VA's evaluation reveals that family caregivers in the general caregiver support program described a lack of connection with the program and expressed the need for more information about resources available to them.

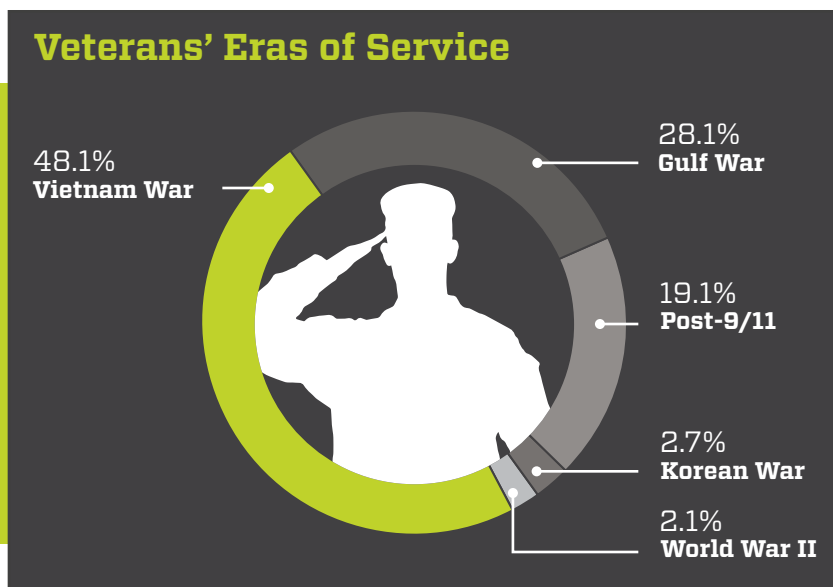
They want more opportunities to interact with other caregivers to learn and become a better caregiver, how to be better at self-care or develop coping skills. Less than half the caregivers in this program were aware of the Caregiver Support Line and more than three of five never speak to their Caregiver Support Coordinator despite their importance and great value to caregivers who communicate with them. Thus, caregivers appear to want but do not necessarily get more help navigating VA and other resources to assist them in managing their veterans' care. The low utilization but high value of respite care by caregivers in this program appears to be the result of misunderstanding the purpose of respite, concerns about the quality of respite and the lack of flexibility in the respite care benefit such as being able to schedule respite on short notice (urgent respite) and longer periods of respite than is currently available.

The table below from the short-term impact study of VA's PCAFC and General Caregiver Support Program shows the awareness and use of available services by family caregivers in both programs.

The DAV survey found that only a very small percentage of all caregivers received any VA support or assistance—just over 10 percent—though caregivers of post-9/11 veterans received significantly more support due to their eligibility for PCAFC. In particular, 31.4 percent of post-9/11 caregivers reported receiving direct payments or stipends compared to just 6.5 percent of pre-9/11 veterans. Similarly, 29.7 percent of post-9/11 caregivers received education on caregiving, compared to just 7.3 percent of pre-9/11 caregivers.

## ELIGIBILITY LIMITATIONS IN VA GENERAL CAREGIVER SUPPORT PROGRAM

Despite the authority for and establishing of the General Caregiver Support Program, the law and subsequent policies continues to treat



family caregivers under this program as incidental to the care of veterans.

## **COUNSELING**

Under current law, VA is authorized to provide counseling, training and mental health services to members of the veteran's immediate family, the veteran's legal guardian and to the individual whose household the veteran certifies as intending to live. In accordance with this law, these services are only provided for: 1) veterans receiving treatment for a service-connected disability if the services are necessary in connection with that treatment and 2) veterans receiving treatment for other than a service-connected disability if the services are necessary in connection with the treatment, the services were initiated during the veteran's hospitalization and the continued provision of the services on an outpatient basis is essential to permit the discharge of the veteran from the hospital.

## **RESPIRE CARE**

The respite care benefit under this program remains oriented to the veteran and not the caregiver and is limited by policy. For example, VA policy defines "a day" of respite as any single day in which respite services are provided to the veteran, that is 6 hours or less in the home, 4 hours or more in adult day health care or 24 hours of care in an inpatient setting. Moreover, the total monthly cost of non-institutional respite services is not to exceed 65 percent of the monthly cost per patient in the nearest VA operated community living center (nursing home). Any additional days needed for respite beyond 30 days or over the cost limitation requires additional administrative and clinical steps—artificial barriers that may affect clinician behavior to provide this needed service to family caregivers.

## **TRANSPORTATION, LODGING AND INCIDENTAL EXPENSES**

While not made part of the General Caregiver Support Program, VA has the authority to pay for transport and associated incidental costs (lodging, food, etc.) of an attendant or other non-veteran, but requires a clinical determination by a VA provider that, due to the veterans mental or physical condition, an attendant is required when transporting the veteran. This restriction limits

the ability for caregivers to defray the cost of traveling to receive caregiver services such as support groups.

- **Congress, VA:** Limitations and restrictions prescribed in statute, regulation and Departmental policies create an inequity in meeting the needs of family caregivers of severely ill and injured veterans in the General Caregiver Support Program. Congress and VA must collaboratively address these barriers to receive effective caregiver supports and services.
- **VA:** According to the Department, unlike PCAFC, there is no formal application process for the General Caregiver Support Program and are therefore not identified and tracked nationally. VA must follow these family caregivers to better understand the value, availability and effectiveness of the General Caregiver Support Program in meeting the needs of family caregivers in caring for severely ill and injured veterans.

## **INTEGRATION OF OTHER SERVICES WITH THE GENERAL CAREGIVER SUPPORT PROGRAM:**

VA offers a relatively robust and innovative set of home- and community-based services that support both the veteran and their family caregivers. However, VA has not taken full advantage of Public Law 111-163, which states, "the Secretary shall collaborate with the Assistant Secretary for Aging of the Department of Health and Human Services in order to provide caregivers access to aging and disability resource centers under the Administration on Aging of the Department of Health and Human Services." This includes VD-HCBS, which is available to veterans of all eras that meet clinical eligibility requirements.

By design, the VD-HCBS program may work well with family caregivers and veterans participating in PCAFC who, according to the RAND report, tend to use more community resources were it not for a bewildering maze of potential services and support that caregivers must navigate. The "maze" results from government programs still in their infancy offering unique services with different eligibility requirements. Though well-intentioned, community-based efforts to serve this population are scattered and largely uncoordinated.

A limited number of VA facilities offer VD-HCBS. Since its inception in 2008, this program has only been available



at 68 of 167 VA Medical Centers. The VA utilizes provider agreements with local agencies of the Aging and Disability Network to administer the program, including providing case management services and oversight of individual budgets. Through VD-HCBS, participating veterans have the opportunity to manage a monthly budget—the amount of which is calculated based on functional and clinical need, hire family members or friends to provide personal care services in the home and purchase goods and services that will allow him or her to remain in the home. It has proven to be a program that can meet the needs of some of VA's most vulnerable populations, including many who would likely be placed in a nursing home without this option. The Secretary of Veterans Affairs recently announced a Departmental goal to make the program available at every VA medical center within the next three years.

- **VA:** VD-HCBS is established at the discretion of local VA facility leadership. Direct and tangible support from VA national leadership is critical to ensure this goal is met including requesting the appropriate funding from Congress.
- **VA:** Eligibility criteria to participate in VD-HCBS must be clearly articulated to veterans and VA healthcare staff.
- **VA:** The Department must use its current authority to create a more integrated and robust General Caregiver Support Program to close the inequity with PCAFC to properly recognize and support family caregivers of severely disabled veterans of all eras.
- **Congress:** Provider Agreement authority to implement VD-HCBS is currently a temporary authority under the Veterans Access, Choice and Accountability Act of 2014 (Public Law 113–146, as amended). Congress must enact permanent authority for VA to achieve its goal to make this program available at every VA medical center within three years and to sustain the program.

#### **LONG-TERM STRATEGY:**

There is a growing movement in the public health to address the needs of family caregivers as a public health concern by looking at population-based public health outcomes to promote their healthy living rather than life without disease.

The Institute of Medicine describes the general functions of public health as assessment, policy and assurance. Having a solid evidence base is necessary to inform policies, programs and interventions. The National Long Term Care Survey (NLTCs) is funded through a Cooperative Agreement between the National Institute on Aging (NIA) and Duke University. It is a longitudinal survey designed to study changes in the health and functional status of older Americans (aged 65+). It also tracks health expenditures, Medicare service use and the availability of personal, family and community resources for caregiving. A supplementary caregiver survey was been added to obtain information on the health and functional status of people who take care of the 65 and older population in a home environment.

The NLTCs in combination with the caregiver supplement to the NLTCs can be used to examine such things as how many hours caregivers spend providing assistance with ADLs and IADLs for chronically disabled elders, as well as the number and percentage of those hours being provided by informal caregivers. It can also be further broken down by primary and secondary caregivers and by relationship, (e.g., spouse, son, daughter, friend, etc.) as compared to paid workers. This enables policy researchers to measure the time burden of providing informal care on caregivers (especially primary caregivers) in relation to the severity of disability and other care recipient characteristics. The relationship between weekly time burden of informal care and self-reported indicators of caregiver stress can then be analyzed. Further analyses could be carried out with respect to relationships among time burden of informal care, self-reported caregiver stress, use/non-use of formal services and funding sources for formal services (public/private).

Finally, the NLTCs/ICS contains numerous questions regarding the primary informal caregiver's perception of the need or lack of formal services and the reason why these services are not being used if they are perceived as needed (e.g., lack of affordability, lack of local availability, etc.). This enables policymakers to estimate (using various different criteria) the potential size and characteristics of the target population for public policy interventions to assist caregivers. As part of the *Independent Budget* (IB), the DAV believes VA should conduct a baseline national survey of veteran caregivers. Considering the demographics of the

enrolled and user population of the VA health care system, attention to caregivers has with reason been drawn to the needs of the aging veteran, but that group represents only one segment—although a large one—of those who receive and provide care; however, the survey should include a special emphasis on caregivers of OEF/OIF veterans. In addition, since caregiving is a lifespan experience, this survey should be conducted at regular intervals.

Because health outcomes and quality of life of veterans with severe injuries and chronic disability also affect the family, a patient and family-centered perspective is essential for quality improvement in redesigning long-term care. We believe policy makers must view family caregivers of severely injured servicemembers as a resource rather than as an unrecognized cost-avoidance tool. In programs where caregivers are assessed, they can be acknowledged and valued by practitioners as part of the health care team. Caregiver assessment can identify family members most at risk for health and mental health effects and determine if she or he is eligible for additional support. Effectively supporting caregivers can result in delayed placement of more costly nursing home care.

Assessment is a critical step in determining appropriate support services. Caregiver assessment is a systematic process of gathering information to describe a caregiving situation. It identifies the particular problems, needs, resources and strengths of the family caregiver and approaches issues from the caregiver's

perspective and culture to help the caregiver maintain his or her health and well-being.

The National Consensus Development Conference for Caregiver Assessment brought together widely recognized leaders in health and long-term care, with a variety of perspectives and expertise, to advance policy and practice on behalf of family and informal caregivers. The Family Caregiver Alliance's National Center on Caregiving designed and convened this conference, held Sept. 7–9, 2005, in San Francisco. The conference generated a report on the fundamental principles and guidelines to advance caregiver assessment nationally and in each state and to serve as a catalyst for change at federal, state and local levels.

- **Congress, VA:** Congress must require and fund a military and veteran caregiver research strategic plan to monitor the health and well-being of family caregivers and the recipients of their love and support; to study current and innovative interventions, their availability, accessibility, and use in supporting family caregivers, and; study military and veteran caregiver from a public health approach.



## DENNIS AND DONNA JOYNER

**D**AV Past National Commander Dennis Joyner was drafted to join the Army during the Vietnam Conflict. While on patrol in Vietnam's Mekong Delta, Dennis became a triple amputee as a result of a land mine explosion. While he says he doesn't remember the explosion itself or flying through the air, he does remember falling back down to the ground and realizing the extent of his injuries.

"That's when I started to lose it," reflected Dennis. "But my sergeant calmed me down by slapping me and reminding me of my family waiting for me back home. My fellow soldiers kept me alive and conscious so I wouldn't go into shock before the medevac helicopter arrived."

Dennis said he didn't imagine anyone would want him after that, he thought he'd be alone forever. But in 1981 Dennis married Donna Shultz, a 28-year-old woman who Dennis says is a saint for coming into his situation knowing how "out of the normal" their lives would be.

"She didn't know me before," said Dennis. "She didn't know the kid who had been more than six-feet-tall and athletic. But she knew me, for me. And I thank her for loving me as I am."

"We [caregivers] all sacrifice a lot. We don't live our lives the same as anybody else," Donna said. "I've given up an awful, awful lot and I would do it again any time."

In 2008, Dennis's rotator cuff in his one good arm blew out, requiring him to have surgery that would leave him unable to take care of himself during recovery. Donna made the decision to quit her career in order to care for Dennis at their home.

"I gave up my job, the income, any pension that I would have received," said Donna. "I will not get as much Social Security when I get to be that age because I had to leave and take care of my husband, because my husband was totally incapacitated and we did not want

him to go to a rehab facility, because he wouldn't get the care at a rehab facility that he would with me."

Post-9/11 veterans and caregivers are afforded benefits for caregivers including training on best care practices and support solutions. But because Dennis was injured in Vietnam, Donna doesn't receive that kind of education.

"We never had any sort of training, nobody even suggested it" said Dennis.

The physical care Dennis requires is much more in-depth than he believes people realize. And all that falls on Donna.

"She has to help me get in and out of my chair, to help me slide into bed or into the shower," Dennis said. "If I get sick, I can't take care of myself, it would all fall on her. Even packing a suitcase or cooking myself a meal, Donna is there to help me, to take care of the physical part of it, all of my basic day-to-day living. I think she—and any caregiver of a disabled veteran from any era—deserve any and all resources, benefits and educational tools available. It just makes sense."







## Final word

**F**amily caregivers willingly and selflessly dedicate themselves to the care of their veteran, putting aside their careers, personal goals and ambitions as well as concern for their own emotional and physical health. They do not seek accolades for the sacrifices they make, in fact they ask for little help and receive even less to alleviate the enormous burden they bear in caring for critically injured or ill loved ones.

So many of these caregivers have soldiered on for decades, without support or relief, and far too many feel the weight of the world on their shoulders. Family caregivers are one of the most critical components of a severely disabled veteran's recovery and rehabilitation and help them live to their highest potential, yet the American public is largely unaware of the many sacrifices these men and women make on a daily basis.

Although there are a number of disparate VA and other federal and state programs designed to provide some measure of assistance or support to caregivers, they are nowhere near adequate to meet the needs outlined in this report. Further, each has its own limitations in terms of resources and eligibility, and the lack of coordination among them effectively leaves

the vast majority of caregivers with no one place to turn. It was for these reasons that Congress created VA's Program of Comprehensive Assistance for Family Caregivers in 2009, however it is severely constrained by limited resources and eligibility. Current law restricts comprehensive caregiver benefits only to veterans who were injured or became ill on or after Sept. 11, 2001. This is an injustice that must be corrected.

Our report first calls for expanding and improving comprehensive caregiver benefits to caregivers of severely ill and injured veterans of all eras. Second, other VA programs and services must be reoriented, expanded and better coordinated to meet the needs of all veterans' caregivers. Third, Congress and VA must create and execute a strategic plan for military and veteran caregiver research, including longitudinal surveys and assessments, to evaluate current programs and services and monitor the health and well-being of caregivers to better inform policymakers.

Working together with Congress, VA, our VSO partners and other key stakeholders, we can ensure that all caregivers of disabled veterans receive the support they have earned and deserve.

# RESOURCES

## **THE IMPACT OF CAREGIVING: STRESS, ISOLATION AND HARDSHIP**

Partners of Veterans with PTSD: Research Findings. Jennifer L. Price, PhD & Susan P. Stevens, PsyD

## **LIMITATION OF EXISTING CAREGIVER SUPPORT**

### **DEPARTMENT OF VETERANS AFFAIRS (VA)**

38 U.S.C. §§ 1782(a), 1782(b), 1712A(b); 38 C.F.R. § 17.38

## **THE LIFESPAN RESPITE CARE PROGRAM**

Alabama; Arizona; Arkansas; Colorado; Connecticut; Delaware; District of Columbia; Hawaii; Idaho; Illinois; Iowa; Kansas; Louisiana; Maryland; Massachusetts; Minnesota; Mississippi; Montana; Nebraska; Nevada; New Hampshire; New Jersey; New York; North Carolina; Ohio; Oklahoma; Pennsylvania; Rhode Island; South Carolina; Tennessee; Texas; Utah; Virginia; Washington; Wisconsin

## **THE ELDERCARE LOCATOR**

[eldercare.gov](http://eldercare.gov)

## **RECOMMENDATIONS**

### **VA CAREGIVER SUPPORT PROGRAM**

U.S. Department of Veterans Affairs, (2011) New VA Support Line Provides Important Assistance to Caregivers [Press Release]. Retrieved from: [www.va.gov/opa/pressrel/pressrelease.cfm?id=2047](http://www.va.gov/opa/pressrel/pressrelease.cfm?id=2047)

U.S. Department of Veterans Affairs, Assistance and Support Services for Caregivers Annual Report Fiscal Year 2012.

## **COUNSELING**

38 United States Code § 1782

## **RESPITE CARE**

VHA Handbook 1176.01 (2011), Spinal Cord Injury and Disorders (SCI/D) System of Care; VHA Handbook 1140.02 (2008), Respite care; VHA Handbook 1140.06 (2006), Purchased Home Health Care Services Procedures; VHA Handbook 1140.03 (2004), Home Health and Hospice Care Reimbursement Handbook.

## **TRANSPORTATION, LODGING AND INCIDENTAL EXPENSES**

38 United States Code § 101

U.S. Department of Veterans Affairs, Assistance and Support Services for Caregivers Annual Report Fiscal Year 2012.

## **LONG-TERM STRATEGY**

Mittelman, M. S., et al. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. JAMA 276(21), 1725–1731.

Journal of Social Work Education, Vol. 44, No. 3 (Fall 2008); Supplement. American Journal of Nursing 108(9), 38–39 (2008).

Family Caregiver Alliance. Caregiver assessment: principles, guidelines and strategies for change. Report from a national consensus development conference. Volume I. San Francisco (CA): Family Caregiver Alliance; 2006 Apr. 43 p. Retrieval from: [www.caregiver.org/caregiver/jsp/content/pdfs/v1\\_consensus.pdf](http://www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf)

# DAV Veteran Family Caregiver Survey

## Full Questionnaire and Final Results

**Conducted Online from May 16 to May 22, 2017**  
**Total valid responses = 1,833**

Survey respondents included family members, relatives and friends who provide care or assistance to a disabled veteran and disabled veterans who have a family member, relative or friend who provides their care and assistance.



1. Are you currently helping to care for or assist a disabled veteran who is a family member, relative or friend, or are you a veteran receiving care or assistance from a family member, relative or friend?

ITEM	RESPONSES
YES, I am a disabled veteran who receives care or assistance from a family member, relative or friend.	<b>51.3%</b>
YES, I provide care or assistance to a disabled veteran who is a family member, relative or friend.	<b>44.3%</b>
NO, I am neither.	<b>4.4%</b>

2. What is the relationship of the caregiver to the disabled veteran who is receiving care and assistance?

ITEM	RESPONSES
Spouse of the veteran	<b>78.5%</b>
Child of the veteran	<b>8.5%</b>
Friend of the veteran	<b>6.6%</b>
Parent of the veteran	<b>1.9%</b>
Sibling of the veteran	<b>2.0%</b>
Other relative of the veteran	<b>2.5%</b>

3. What types of care or assistance are provided by the caregiver to the veteran? Please choose all that apply.

ITEM	RESPONSES
Shopping and home maintenance	<b>84.0%</b>
Prepare and serve food and meals	<b>82.2%</b>
Coordinate health care services and medications, including transportation to appointments	<b>78.0%</b>
Other types of help and assistance	<b>65.7%</b>
Manage money and finances	<b>58.7%</b>
Provide supervision or protection due to neurological or mental disorders (e.g.-TBI, dementia)	<b>39.7%</b>
Help with bathing and dressing	<b>41.1%</b>
Provide direct medical care or treatments	<b>33.1%</b>

4. For approximately how many years has the family caregiver been providing care or assistance to the disabled veteran?

**Average Response = 9.8 years**

5. On average, how many days a week does the family caregiver provide care or assistance to the disabled veteran?

**Average Response = 6.5 days per week**

6. On average, how many total hours per week does the family caregiver provide care or assistance to the disabled veteran?

**Average Response = 45.4 hours per week**

7. Does the family caregiver receive any of the following support or assistance from the Department of Veterans Affairs, and is the level of support enough to meet the caregiver's and veteran's needs? Please choose all that apply.

ITEM	YES, receiving enough of this support	YES, receiving this support, but it is not enough	NO, not receiving this support
Caregiver Education	6.7%	5.0%	88.3%
Medical Training Direct Financial Support (Stipends)	4.7%	6.5%	88.8%
Home Health Aide	3.3%	5.3%	91.4%
Respite Care	3.1%	3.9%	93.0%
Medical Training	0.1%	3.1%	96.8%

8. In your opinion, if there was no family caregiver providing the disabled veteran with care and support, would the veteran need to be placed into institutional care, such as a skilled nursing or assisted living facility, either now or in the future?

ITEM	RESPONSES
YES, the veteran would require institutional care in the FUTURE	49.3%
YES, the veteran would require institutional care NOW	25.7%
NO, the veteran is capable of living independently.	25.0%

9. If the following services were made available, how important would each be in helping to support the family caregiver as they care for and assist the disabled veteran? Please mark all that apply.

ITEM	VERY IMPORTANT	IMPORTANT	SOMEWHAT HELPFUL, BUT NOT THAT IMPORTANT	NOT NECESSARY
Direct Financial Support (Stipends) to Caregivers	62.2%	21.1%	7.1%	4.7%
Health Insurance for Caregivers	48.1%	20.1%	9.8%	17.0%
Medical Training for Caregivers	39.9%	30.1%	14.3%	10.6%
Education on Caregiving	39.1%	30.6%	14.0%	10.9%
Home Health Aide Support	37.8%	29.5%	15.0%	13.4%
Respite Care for Caregivers	36.4%	23.3%	16.8%	17.5%
Mental Health Services for Caregivers	34.2%	24.9%	17.3%	18.2%
Peer Counseling for Caregivers	27.6%	28.6%	22.4%	16.1%

10. Thinking about all the time, effort and sacrifices made by the family caregiver, do you think that may have limited or negatively impacted other aspects of the caregiver's life and how significant were those impacts? Please respond to all that apply.

ITEM	YES, significantly limited or negatively impacted	YES, but only somewhat limited or negatively impacted	NO, did not limit or negatively impact
Financial Security	52.7%	29.5%	14.6%
Job, Career or Work	48.3%	29.3%	20.7%
Friendships and Social Relationships	46.1%	38.1%	13.8%
Family Life and Relationships	43.8%	39.0%	14.5%
Mental Health and Well Being	41.6%	38.0%	16.7%
Physical Health and Fitness	41.2%	40.4%	15.7%
Educational Pursuits	29.4%	26.7%	39.4%



11. Does the veteran receive VA disability compensation and if so, what is the disability rating?

ITEM	RESPONSES
YES, rated 100%	61.7%
YES, rated 70% to 90%	17.2%
YES, rated 50% to 60%	7.1%
YES, rated 10% to 40%	5.2%
NO, does not receive VA disability compensation	8.8%

12. During what war or era did the veteran suffer the injury or illness that resulted in their disability?

ITEM	RESPONSES
Before or During World War II	1.8%
After World War II but Before the Korean War	0.2%
During the Korean War	2.5%
After the Korean War but Before the Vietnam War	2.1%
During the Vietnam War	46.3%
After the Vietnam War but Before the Gulf War	12.2%
During the Gulf War	11.2%
After the Gulf War but Before Sept. 11, 2001	4.7%
On or After Sept. 11, 2001	19.1%

13. How old are you? Please answer for yourself, whether you are the caregiver or the disabled veteran.

**Average Response = 59.5 years**

14. What is your gender?

ITEM	RESPONSES
Female	50.6%
Male	48.1%

15. Do you have children living with you in your home? Choose the response that best fits your situation.

ITEM	RESPONSES
NO, I do not have any children living in my home.	<b>64.9%</b>
YES, I have children who are younger than 12 and are living in my home.	<b>15.1%</b>
YES, I have children who are between 12 and 18 and are living in my home.	<b>11.1%</b>
YES, I have children who are over 18 and living in my home.	<b>9.0%</b>

16. If you are interested in sharing your experience being or having a family caregiver with DAV, please enter your name and contact information below, including phone number and email address.

**Number of Responses: 475**

17. If you would like to share any other comments, you may do so below.

**Number of Responses: 797**





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**NATIONAL HEADQUARTERS**

3725 Alexandria Pike  
Cold Spring, KY 41076  
859-441-7300  
Toll Free 877-426-2838

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