



# Everyday Heroes: Supporting the Veteran Caregiver Community

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Statement of

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For the Record

United States House of Representatives  
Committee on Veterans' Affairs

With Respect To

Everyday Heroes: Supporting the Veteran Caregiver Community

WASHINGTON, D.C.

Chairman Bost, Ranking Member Takano, and members of the committee, on behalf of the men and women of the Veterans of Foreign Wars of the United States (VFW) and its Auxiliary, thank you for the opportunity to provide our comments on this important topic.

As a grateful nation, our mission is to support those who have defended our freedoms but how are we supporting the caregivers who have dedicated their lives to caring for our nation's veterans? The Department of Veterans Affairs has come a long way in the services it provides to support the care of our nation's veterans but there is still more work to be done. Caregivers make up a variety of people from spouses to children, parents, and even neighbors who work tirelessly to ensure that veterans have the best quality of life. Veterans who require caregivers are not only part of the aging population of 65 years and older but also include Post 9/11 veterans with critical injuries like Traumatic Brain Injury (TBI), Post Traumatic Stress Disorder (PTSD), gunshot wounds, amputations, spinal cord injuries, etc.

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## Background

Prior to 2010, the VA had an informal caregiver program. Caregivers assisting veterans who served prior to 9/11 tend to resemble civilian caregivers where they relied on local programs to assist. Informal caregiver training and resources including family caregivers of veterans were eligible for VA counseling and mental health services, and reimbursed attendants for travel expenses related to authorized VA treatment for the veteran were available by the VA. However, there was no dedicated program to address the unique needs of the veterans. When the veterans were unable to care for their daily needs, decisions were made by caregivers to ensure that their loved one would not be institutionalized. However, this resulted in emotional, financial, and physical strain on caregivers that led to burnout.

It was in March 2007 when President George W. Bush established the President's Commission on Care for America's Returning Wounded Warriors, which was tasked with providing a comprehensive review of the care provided to injured military personnel returning from the wars in Afghanistan (Operation Enduring Freedom/OEF) and Iraq (Operation Iraqi Freedom/OIF). The Commission resulted in six recommendations: (1). Modernizing and improving the disability and compensation systems; (2). Aggressively preventing and treating post-traumatic stress disorder and traumatic brain injury; (3). Significantly strengthening support for families; (4). Immediately creating comprehensive recovery plans to provide the right care and support at the right time in the right place; (5). Rapidly transferring patient information between the Departments of Defense (DoD) and Veterans Affairs (VA); and (6). Strongly supporting Walter Reed by recruiting and retaining first-rate professionals through 2011. Through these recommendations, the President was able to get a 77% budget increase to support veterans' healthcare.

In May 2010, Congress passed the VFW-supported Caregivers and Veterans Omnibus Health Services Act of 2010 requiring that VA establish a range of new services to support caregivers of eligible Post 9/11 veterans. There were strict guidelines to eligibility requirements, 86 percent of the veterans who are enrolled in the caregiver program have a service-connected disability rating of 70 percent or higher. A veteran must have incurred or aggravated a serious injury while serving in the military on or after Sept. 11, 2001. Due to the serious injury, the veteran must also now require assistance with the management of their personal care and functions involved in daily life. This assistance must be needed for a minimum of six continuous months based on a clinical decision, and then receive continuous care from a Patient Aligned Care Team or another VA health care team which is in the best interest of the veteran. The veteran must also agree to receive ongoing care at home by the designated family caregiver, and those services provided by the caregiver may not be provided by any other individual or entity. The payment structure was based on a 3-tier system which was determined by how many hours of care a week were needed based on the clinical decision.

To comply with this legislation, VA created two new caregiver programs. The first, the Program of General Caregiver Support Services (PGCSS) established peer support mentoring, skills training, coaching, telephone support, online programs, and referrals to available resources to caregivers of veterans. The second, the Program of Comprehensive Assistance for Family Caregivers (PCAFC) expanded benefits and services to include a Caregiver Support Line, a monthly stipend, health care coverage, legal and financial planning services, and travel expenses. However, members of VFW, some of whom were from World War II, the Korean War, the Vietnam War, the Gulf War, and various other conflicts, expressed concerns that there was no justifiable reason to exclude otherwise deserving veterans from program eligibility simply based on the era in which they served.

After the push for veterans of all eras to participate in the PCAFC and as a part of the VA MISSION Act of 2018, the PCAFC was then expanded to veterans of all eras. In July 2020, VA published the final rule for the caregiver expansion program after a 16-month delay. The first phase of the expansion was implemented in Oct. 2020, adding veterans who served after May 7, 1975, and before Sept. 11, 2001. However, eligibility criteria requirements for acceptance into the caregiver program became rigorous. VA's definition of a serious injury for participation in the caregiver program as, "any injury, including traumatic brain injury, psychological trauma, or other mental disorder, incurred or aggravated in the line of duty in the active military, naval, or air service on or after September 11, 2001, that renders the veteran or service member in need of personal care services." That definition was critical because it did not successfully define the inclusion of those who need the assistance of a caregiver due to debilitating illnesses that render a veteran unable to perform activities of daily living without the assistance of a caregiver, such as Parkinson's Disease and Amyotrophic Lateral Sclerosis (ALS). While VA has never considered non-mental health illnesses when determining eligibility for the caregiver program, the Department of Defense's Special Compensation for Assistance with Activities of Daily Living (SCAADL) program did.

In fall 2021, VA officials announced they would review all "legacy" participants — individuals admitted before October 2020 — to ensure they still met the criteria for participation. At the time, it was estimated that about one-third of the nearly 20,000 legacy participants could be dropped from the program because of eligibility changes. These issues have led to VA implementing a moratorium on involuntary revocations from the program until VA was able to analyze the thousands of recent revocations to determine if veterans are being erroneously removed from the program.

While the VFW certainly agrees that veterans who have recovered from injuries and illnesses should be put on a path to achieve independent living and no longer require the assistance of a caregiver, such decisions must be made when the veteran and the caregiver agree and not by VA employees who lack the proper training and medical expertise to make such decisions. When a decision is made to graduate a veteran from the caregiver program,

VA must ensure veterans and their caregivers are given the training and resources, such as employment training and independent living counseling, to ensure veterans can properly transition from needing a caregiver to performing activities of daily living without the assistance of others.

On September 21, 2022, VA issued an interim final rule by extending eligibility for legacy participants, legacy applicants, and their Family Caregivers, and the applicable benefits afforded to such Family Caregivers, to include the monthly stipend, by three years. In Oct. 2022, the second phase of the implementation expanded the PCAFC program to all veterans leading to more than 74,000 veteran caregivers in fiscal year 2023. VA's Caregiver Annual 2023 Report indicated that 98 percent of PCAFC applications were processed within 90 days or less. The Caregiver Support line has received more than 150,000 calls, with the top three reasons being appeals, application status, and referrals. The national training curriculum has been provided in multiple languages and the approximately 2500 Caregiver Support Staff are receiving training to provide the adequate assistance and support needed to assist the caregiver.

### **Economic and Personal Hardships of Caregivers**

Parents and children of veterans are impacted in many ways when they become caregivers. Parents raise their children to become independent with the goal of the child caring for the parent's during their aging years but when a life-altering injury or illness occurs unexpected things happen. Sometimes these older parents have a difficult time caring for themselves and it becomes an emotional strain and burden on them to accept the role of caregiver to their child. Challenges that caregivers face are managing their time, lack of privacy, sleep deprivation, depression and isolation, and being afraid to ask for help. Children of veterans who suffer from an injury or illness may have to go through the process of growing up too soon by helping more around the house, some have a hard time understanding the significance of the injury or illness and the impact it has on them, and not having that emotional connection they yearn for as they are figuring out who they are in this world. Family and individual mental health services offer the support caregivers need, as they travel the road to recovery or a sense of normalcy.

The economic hardships that veterans, their families, and caregivers face is substantial; families sacrifice a lot when a veteran is disabled and needs care and supervision. Often, the spouse, child, parent, or family friend must quit their job to meet the need. This sacrifice leaves a hole in the financial picture of the family. The Caregiver stipend should be increased to offset this sacrifice. Also, when a caregiver stops their outside employment, there is no contribution to Social Security, which is concerning for the caregiver. 38 CFR 71.40 (c)(4)(1) and (2) report that the stipend amount for the PCAFC provides two levels of benefit. The VA approved Primary Caregiver for the veteran can receive a monthly stipend which is calculated by multiplying the monthly stipend rate by 0.625 and if the VA

determines that the eligible veteran is unable to self-sustain in the community, the Primary Caregiver stipend would be calculated by multiplying the monthly stipend rate by 1.00. These caregivers are taking the place of a VA services and should be compensated as such.

## **Current VA Programs**

The VA Caregiver Program is a critical service provided to veterans and their families. For veterans, their families, caregivers, and future enrollees, the VA Caregiver Support Programs are critical. Improvements are necessary for the Caregiver programs to include Respite Services, Non-primary Caregiver Employment Support, and Modernization and Standardization of the systems used to process and adjudicate Caregiver Claims including Notification Letters. Caregivers are often on duty for 24 hours a day, the mental strain of caring for a loved one is complex and overwhelming at times and can lead to depression and burnout. The PCAFC provides respite services and CHAMPVA coverage. CHAMPVA is a cost-share program and is not insurance coverage. We know that an individual's mental health has a direct correlation to an individual's physical health. Respite services, if approved, are authorized up to 30 days of care in a calendar year and must be arranged in advance. The current types of Respite Care offered are: 1 visit of 30 days in a Community Living Center (VA Nursing Home); 10 short stays of 3 days each; or you may have a Home Health Aide come to your home and stay for up to 6 hours in a row, day or night, with each of these visits counting as 1 day. Families can divide their approved respite care among the different types of Respite Care. When listening to the concerns of Caregivers the 30-day limitation for respite services does not adequately allow for unpredicted illnesses or emergencies that may arise that could impact their ability to complete their roles as a caregiver.

VA approved Non-Primary Caregivers for veterans have limited protection if they must miss work to step in for the Primary Caregiver. There is no protection of their employment or financial offset when they do leave or miss work to provide this service. Providing employment protection to Non-Primary Caregivers under PCAFC would additionally relieve the mental burden and concerns of financial insecurity of those Non-Primary Caregivers, who do not receive all the same benefits that the Primary Caregivers receive under PCAFC.

Unlike the process that the Veterans Benefits Administration (VBA) has in place to process Disability Claims, Appeals, and other benefits administered under the Department of Veterans Affairs; the Caregiver Applications and Appeals process is administered under the Veterans Health Administration and does not provide the ability for Veterans Service Organizations and Accredited Representatives to follow these claims through the adjudication process, as seen in the VBA systems.

The PCAFC claims are received and processed at the local VA Medical Centers, which lack standardization and oversight like compensation claims. Inconsistency in adjudicating these claims and processing notifications of decisions is causing undue mental and financial

burden on these veterans, families, and caregivers. Much like the VA Disability Claims and Appeals letters sent to notify veterans of rating decisions, the Caregiver Notification letters are intended to communicate crucial information about the veteran's caregiver status, required process, and benefits within the program. However, the complexity of these letters often makes it difficult for the veteran to comprehend the status details and implications if further information or action is required.

The VFW and the Veterans Service Organizations (VSO) community advocated for the simplification of decision notices, as well as standardized verbiage when recognizing the service of the caregivers and the loss of the veteran. It is understood that all the complex legal language is required to be included but recognition of service, and condolences should be upfront and not lacking compassion. Some letters that caregivers or veterans have received do not even include condolences for the loss and are straight to the benefits decision. Many decision letters do not provide adequate information for veterans, families, or caregivers to determine why the claim for caregiver status was declined. Some will come with a one-sentence explanation with no direct "why" which leaves even VSOs and accredited service officers guessing on how to proceed.

And finally, standardization of the veteran eligibility process should be done as well. 38 CFR 71.20 reports veteran eligibility criteria for the PCAFC program. This regulation reports that for an individual to be eligible they must have had a serious injury incurred or aggravated by service, and VA defines serious injury as a 70 percent VA rating or a combination of 70 percent for disability, and they must be in need of personal care services for a minimum of six continuous months based on any ONE of the following: an inability to perform an activity of daily living (ADL); or a need for supervision, protection, or instruction. VA defines the inability to perform ADLs as a veteran or service member who requires personal care services each time he/she completes one or more of the following: dressing/undressing, bathing, grooming oneself in order to keep oneself clean and presentable, adjusting any special prosthetic or orthopedic appliance, that because of the disability, cannot be done without assistance, toileting, feeding oneself due to loss of coordination of upper extremities, extreme weakness, inability to swallow or the need for non-oral means of nutrition or mobility. The inability to self-sustain in the community is defined by VA as the veteran requiring personal care services each time, he/she completes three or more of the seven activities of daily living listed above and is fully dependent on a caregiver to complete ADLs or has a need for supervision, protection or instruction. These criteria set for ADLs are clearly defined yet the inability to self-sustain in the community based on supervision, protection, or instruction is not defined at all.

## **VFW Recommendations**

The role of the caregiver is crucial to ensuring that veterans have the dignity of staying in their own homes while receiving care. We have listed some possible solutions that could

further support the work and great service caregivers provide.

1. Congress should increase the stipend amount while providing coverage for Social Security points.
2. Recognizing that the role of a caregiver is highly stressful and VA should provide more comprehensive insurance coverage for the caregivers, providing for physical and mental health coverage.
3. Increase the number of respite days or allow a flex increase for those emergency or unpredictable situations that may arise. This will assist with the burden of care and help to improve the mental health of caregivers.
4. Provide employment protection services to approved Non-Primary Caregivers to help reduce financial burdens. This would help increase mental health and economic stability.
5. Standardize the caregiver program to include letters, along with modernizing the digital access of the PCAFC adjudication process like those that are accessible to VSOs through VBA.
6. Define the eligibility criteria for supervision, protection, or instruction, as it is not well defined. Also, standardize the implementation of the criteria as it should be standard practice, nationally.

The VFW urges Congress and VA to be mindful of the sacrifices that families, friends, children, etc. selflessly accept to care for and support our nation's veterans. The PCAFC provides a robust number of services that our caregivers greatly need and improving these services will allow for a greater quality of care. The VFW strongly urges Congress to pass H.R. 8371, The Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act, which would enhance and reform the delivery of services at the VA by prioritizing veterans, their families, their caregivers, and their survivors. This bill would increase of expenditure cap for non-institutional care alternatives to nursing home care. It would authorize the Secretary to enter into agreements with Aging and Disability Resource Centers, area agencies on aging, or State agencies, as well as centers for independent living, Indian Tribes or Tribal organizations. It would also provide coordination with assistance and support services for caregivers, and provide a centralized website to access information and provide improvements to the Homemaker and Home Health aide program. These are critical improvements the program needs, and caregivers have waited long enough, and should not have to wait for another Congress to provide this help.

Chairman Bost, Ranking Member Takano, this concludes my statement. Again, thank you for the opportunity to offer our comments on this issue to the committee.

**Information Required by Rule XI2(g)(4) of the House of Representatives**

Pursuant to Rule XI2(g)(4) of the House of Representatives, the VFW has not received any federal grants in Fiscal Year 2024, nor has it received any federal grants in the two previous Fiscal Years.

The VFW has not received payments or contracts from any foreign governments in the current year or the preceding two calendar years.