

STATEMENT FOR THE RECORD

QUALITY OF LIFE FOUNDATION

HOUSE COMMITTEE ON VETERANS AFFAIRS

EVERYDAY HEROES: SUPPORTING THE VETERAN CAREGIVER COMMUNITY

SEPTEMBER 25, 2024

Chairman Bost and Ranking Member Takano, and Members of the Committee, thank you for allowing Quality of Life Foundation's Wounded Veteran Family Care Program (QoLF WVFCP) to present our testimony to you about veteran caregivers and their needs through this statement for the record. Quality of Life Foundation is a national non-profit organization that was founded in 2008 to address the unmet needs of caregivers, children, and family members of those who have been wounded, become ill, or were injured serving this nation. Since 2008, QoLF's mission evolved to include working directly with veterans and caregivers as they attempt to apply for and navigate the Program of Comprehensive Assistance for Family Caregivers (PCAFC) and other clinical support programs within the Department of Veterans Affairs. Serving all generations, we focus on those with significant wounds, illnesses, or injuries, and find ourselves often assisting veterans with the most complex needs.

As one of the few organizations working exclusively within the Veterans Health Administration (VHA), QoLF has been a prime witness to and help for caregivers utilizing many of the programs and services available within VHA. While we do NOT provide clinical recommendations of any kind, our role is to ensure that veterans and their caregivers are prepared for the PCAFC process, assist in drafting clinical appeals to ensure VHA is following its own regulations and directives, and assist veterans and their caregivers in navigating other programs and supports available to them.

Our role allows us to see the positive things which happen when veterans and their caregivers are connected by caring, passionate providers and social workers to the programs and services that enhance both their care and quality of life. PCAFC, Respite, Veteran Directed Care, and the Homemaker Home Health programs are just some of the programs supporting veterans in their homes and serve as a lifeline for veterans and their caregivers in need. Unfortunately, we also see what happens when those especially vulnerable veterans and their caregivers are not connected to these vital resources.

Overview

The recent RAND study, [America's Military and Veteran Caregivers: Hidden Heroes Emerging From the Shadows](#), highlights that veteran caregivers often spend their time on a range of activities, including providing personal care, managing medical tasks, and handling administrative duties related to healthcare. Many caregivers also reported high

levels of emotional and physical strain, with significant time dedicated to supporting their loved ones' mental well-being. This study underscores the need for additional support and resources for these caregivers to effectively manage their responsibilities. The RAND study validates the trends that Quality of Life Foundation's staff see on a daily basis when assisting veterans and their caregivers. And, as QoLF has done previously, we will again make recommendations for legislation that can assist those caregivers, this time with the backing of evidence from the recently released RAND study.

Problems:

1. **Veteran caregivers experience financial hardships.** Military and veteran caregivers lose an average of **\$13,105 annually** in lost wages and productivity due to their caregiving responsibilities. (RAND, viii) **35%** of military and veteran caregiver households live at or below **130%** of the federal poverty level, and less than **33%** of those households are using government programs that provide financial assistance, like the Supplemental Nutrition Assistance Program, or SNAP. (RAND, viii-ix) In addition, fewer than half of veteran caregivers are able to take advantage of workplace accommodations, such as flexible hours, telecommuting, shortened work weeks, which would make their caregiving easier, thus contributing to income loss and higher caregiver burden. (RAND, ix)
2. **Veteran caregivers experience a high mental health burden.** Specifically, 43% of military and veteran caregivers whose care recipients were under 60 met the criteria for depression. 20% of those caregivers had thought about suicide within the past twelve months, and 36% said they needed mental health help but did not access it. (RAND, vii). And 25% of caregiving military and veteran caregiving parents reported that their children needed mental healthcare. (RAND, viii)
3. **Veteran caregivers do not feel valued by veterans' healthcare teams.** Veteran caregivers whose care recipients use VHA healthcare as their primary healthcare believe their input on the veteran is not valued. These caregivers also believe they are not included in healthcare decisions made by the veteran's healthcare team, despite being responsible for carrying out the treatment plan. Many caregivers feel that they must follow up on care and paperwork from the VHA healthcare team, and that their veterans experience healthcare delays. (RAND, x) Many of these caregivers are caring for veterans with complex wounds, illnesses, and injuries.

Recommended Solutions

1. **Pass the Veteran Caregiver Re-education, Re-employment, and Retirement Act (H.R. 9276).** When the original legislation (PL 111-163) was passed creating the VA Caregiver Support Program (CSP), the unintended consequence of making the income from PCAFC an unearned income stipend was that included caregivers have no means to save for their own retirement or contribute to Social Security if there is no other earned income in the home. (Combat Related Special Compensation, VA

Disability, and Social Security Disability Income are all considered unearned income and are the only income sources for many veteran-caregiver households.) Because no prior program had existed to support caregivers in this way across the United States, the consequences for retirement and Social Security contributions were not understood at the time of the legislation. Caregivers first learned of the consequences after they attempted to make contributions to their pre-existing retirement accounts and were hit by fees for making unauthorized contributions.

Additionally, caregivers have gaps in their resumes and lose their employment certifications while caregiving for their loved one. When their loved one either passes away or returns to independent functioning, caregivers need to return to the workplace and have to address these issues.

Since the creation of the CSP, caregivers have been concerned about being able to prepare themselves for their retirement years. The Veteran Caregiver Re-education, Re-employment, and Retirement bill would study the issue of allowing caregivers to make contributions to Social Security and other types of existing retirement accounts.

This bill would allow caregivers to have funds provided to renew their professional certifications, study the feasibility of caregivers being allowed to participate in a Department of Labor returnship program, and create a study to explore VA incorporating former caregivers into the VA workforce as personal care attendants which would assist VHA in filling gaps in its workforce.

Ultimately, QoLF sees this bill as a way to support caregivers who voluntarily supported their veterans through wounds, illnesses, and injuries, while preventing them from falling into poverty and necessitating that they rely on public assistance programs after caregiving whether through aging out or through their veteran passing away. QoLF is not asking Congress to fund retirement for these caregivers, simply to find a pathway so caregivers have the option of funding their own retirement accounts.

2. **Pass the Credit for Caring Act (H.R. 7165).** This legislation provides up to a \$5000.00 non-refundable federal tax credit for working family caregivers. The bill would help to offset a portion of caregiving expenses that veteran caregivers are paying out of pocket. It would cover home health aides, respite care, adult day care, etc.
3. **Legislate the language surrounding Activities of Daily Living and the level of assistance needed by the veteran to ensure the intent of Congress to allow “regular assistance with an ADL” to be the standard for PCAFC eligibility rather than the current assistance standard of “each and every time a veteran performs an ADL.”** The requirement that a caregiver must assist a veteran with an Activity of Daily Living (ADL) “each and every time” it is completed for eligibility in PCAFC was reviewed by the courts. The *Veteran Warriors, Inc. v. McDonough* ruled

that this strict interpretation of assistance with ADL's under VA's regulation was allowed under the legislation creating PCAFC. However, VA Central Office CSP has acknowledged that this strict interpretation is keeping veterans, especially older veterans, out of the program and penalizing veterans for being able to do anything for themselves which impedes progress in rehabilitation and potentially causes patient harm. Prior to the 2020 regulation governing PCAFC, the ADL standard for PCAFC was "regular assistance" which was in line with the standard for Supervision, Protection, and Instruction.

By legislating this language, PCAFC would be opened to those caregivers who have previously been denied participation, thus allowing them to participate in PCAFC which would allow them financial compensation for responsibilities that they have been fulfilling for free and that has caused them to miss time at or leave their job, impacting their income.

While QoLF would not normally ask Congress to legislate this language to such specificity, we do so in this instance. The regulation governing PCAFC has changed four times since the creation of this program in 2011, and we are currently waiting for a new proposed regulation to be published in the immediate future. In order to keep changes from being made each time there is new leadership at the helm of VA, we ask that Congress write the legislation into statute, preventing the legislative language that exists now from being continually re-interpreted by VA and necessitating the constant pauses in PCAFC that have occurred since the programs inception.

- 4. Establish a cadre of specially trained case managers,** similar to the Federal Recovery Care Coordination Program (FRCP) and potentially linked to the lead coordinator who can take on the most difficult cases. This would benefit the individual caregiver and veteran while freeing up the care managers and other case managers to serve more veterans. While most caregiver and veteran dyads can be accommodated by a simple phone call to a social worker or care manager, those with the most complex needs often need an individual with the training, competency, desire, and authority to request waivers, explore options, and develop integrated care plans.
- 5. Ease the process of obtaining a case manager.** It is difficult to obtain a case manager and very little public information exists to educate the veteran and the caregiver on case management. As a result, caregivers do most of the case management for their care recipients.

If a caregiver were to look for a case manager the following might ensue: The Richmond, Virginia VAMC homepage only mentions case management once as a subheading for Post 9/11 M2VA Care. There is no mention of co-morbid complex care case management or of disease specific case management. If you click on Post 9/11 M2VA case management, the description is not about multiple

disease/condition/injury care, but more a description of transitioning back into civilian life after serving in the military. For those veterans that entered Afghanistan in 2001 or Iraq in 2003, should they look for case management services for multiple complex care needs, the description would not be one that would likely cause them to connect with the M2VA program or case managers. For any other veteran, not post 9/11, there is no mention of case or care management programs on the front page for that facility.

So how exactly does a veteran know that these programs exist, know to ask for them, and know how to find them?

- 6. Establish a “Pathway to Advocacy” for outside organizations to officially assist veterans and caregivers within VHA.** QoLF strongly supports the recent Senate introduction of the **CARE Act of 2023** which includes a provision requiring the Secretary to develop a process to train and recognize non-profit organizations to assist in the navigation of programs and services within the Veterans Health Administration, allowing support and assistance for caregivers in obtaining care for their veteran care recipients. While QoLF currently uses Releases of Information to advocate on behalf veterans and caregivers, such a process would allow certified organizations to work more effectively WITH social workers and care managers to better support the population we all serve.
- 7. Pass the Elizabeth Dole Home Care Act (H.R.542).** QoLF strongly supports the passage of this act which provides expanded mental health care and respite care for veteran caregivers in the Program of General Caregiver Support Services who do not currently receive mental health care in support of their caregiving duties. This also honors veterans’ decisions to be cared for in their homes by eliminating the home care cost cap that currently forces a veteran into a nursing home. Additionally, QoLF offered language in this bill that would ensure if veterans and caregivers were found ineligible for PCAFC, other programs the care recipient was qualified for would have to be identified and put in place before the caregiver could be removed from PCAFC or as a result of a denial of PCAFC. This would allow caregivers to feel supported.

Conclusion

Quality of Life Foundation would like to thank the Committee for allowing us to offer these suggestions to improve the lives of military and veteran caregivers as well as the veterans for whom they care. We would be happy to answer any questions that you have.

