# STATEMENT FOR THE RECORD

# QUALITY OF LIFE FOUNDATION

# JOINT COMMITTEES ON VETERANS AFFAIRS

# QUALITY OF LIFE FOUNDATION'S LEGISLATIVE PRIORITIES FOR VETERANS AND CAREGIVERS IN 2024

# MARCH 2024

Chairmen Tester and Bost, Ranking Members Moran and 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 legislative priorities for the year to you 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 mostly on those with significant wounds, illnesses, or injuries, and find ourselves often assisting those with the most complex needs.

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

Our role allows us to see the positive things that can happen when veterans and caregivers are connected by caring and 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 that support veterans in their homes and can serve as a lifeline for veterans and caregivers in need. Unfortunately, we also see what can happen when those especially vulnerable veterans are not connected to those vital resources.

Our legislative recommendations fall into three categories: recommendations that involve all of the Veterans Health Administration (VHA), recommendations that apply only to VA's Caregiver Support Program (CSP), and recommendations that are specific to respite care.

Primary Request

Quality of Life Foundation's primary request for the legislative year 2024 is the passage of the pending Senator Elizabeth Dole 21st Century Veterans' Healthcare and Benefits Improvement Act. While we know that the committee is awaiting the final CBO score, and we know that not every provision in the draft legislation will make it into the final package for consideration due to budget constraints and the limited amount of mechanisms to fund new programs and mandates, QoLF supports the passage of as much of the omnibus package as is possible to fund, especially those components of the omnibus package that were originally part of the Elizabeth Dole Home Care Act (S141 and H542) as well as the CARE Act of 2023 (aka Veteran Caregiver Application and Appeals Reform Act of 2023, S1792).

VHA-wide Requests/Recommendations

1. **Establish a "Pathway to Advocacy" for outside organizations to officially assist veterans and caregivers within the Veterans Health Administration.** QoLF strongly supports the Senate's CARE Act of 2023 (S1792) which includes a provision requiring the Secretary of the VA 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. While QoLF currently uses Releases of Information to advocate on behalf of veterans and caregivers, such a process would allow certified organizations to work more effectively WITH social workers, providers, and medical administrations to better support the population we all serve.

   Currently, the Veterans Benefits Administration (VBA) has a system in which organizations and their officers can be certified and allowed to operate on behalf of veterans, as well as paperwork that allows veterans to designate representatives to advocate on their behalf. When that paperwork is filed, VBA has little recourse to not honor that request. The same pathway to advocacy for veterans and caregivers does not exist on the VHA side of the Department. As such, as advocates in VHA, we request that clients fill out Releases of Information (ROI) so we may interact with VHA employees on behalf of the veterans and caregivers we serve. What we routinely find is that VHA employees and facilities can choose to not interact with designated representatives who have ROI's, even when veterans and caregivers are present and giving VA employees permission to release that information and to allow advocacy on their behalf.

   QoLF would like to see this provision be included in the Veterans' Package of legislation that is pending before Congress.

2. **Direct the Secretary of the VA to establish an easily accessible, standardized, and centralized pathway for outside, non-VA records to be incorporated into the veteran's VHA medical record and require that Veterans Health Administration honor its "Duty to Assist" veterans and caregivers in getting those records integrated into the VHA medical record.** While Quality of Life Foundation approaches the inclusion of outside medical records from the lens of the

application process of the PCAFC, the importation of these non-VA medical records into the VA medical record crosses all VHA programs, and is not limited to its application to PCAFC.

Many veterans that QoLF serves have multiple serious medical conditions and multiple insurance options, including TRICARE, Medicare, and/or private health insurance. As a result, many use a hybrid collection of medical providers. As such, all of the treatment records need to be available for the Veterans Health Administration to consider the clinical needs of the veteran and for the VA CSP to make an informed decision on whether or not the veteran's needs for clinical assistance rise to the level of acceptance into PCAFC.

Even if VHA is aware that non-VA or even VA Community Care Network (CCN) records exist, there is no easy way for veterans and caregivers to get those records submitted to VA and into the VHA medical record in a timely manner. In the VBA, there is a "duty to assist" a veteran to seek care and collect those records. In VHA, that would translate to VHA staff, and in cases of CSP, CSP staff, helping a veteran and caregiver gather outside records and ensuring their appropriate placement in the VHA medical record for consideration in clinical services, treatment, and evaluations.

Additionally, the placement of the veteran's outside medical records in their VHA medical record, and where in the electronic health record or which VA system it is stored in, varies from facility to facility. Outside clinical records must be received and uploaded in the VA medical records system in order to be considered for any clinical purpose. However, EACH VAMC Information Technology Office determines who has the ability to upload outside records, leading to variations in procedures and the time needed to complete the process.

Within the VA CSP alone, some facilities allow the CSP office to directly upload the records into the medical records system, while others require the Primary Care Manager (PCM) first go through the records to determine what needs to be scanned in and then send the applicable records to the VA Records office at the facility for scanning. Other facilities require that outside records be taken directly to VA Records. Further, none of these circumstances allow the veteran and caregiver to see the uploaded records, as they do not have access to the system where the records are placed either electronically or in person.

Directing SecVA to establish a uniform process for inputting outside records electronically and housing them in a specific manner would allow all clinical data about a veteran to be easily accessed and utilized to make appropriate clinical decisions in a timely manner across all VHA programs.

CSP and PCAFC Specific Recommendations

Because Quality of Life Foundation operates mostly in the Caregiver Support Program space, we have highlighted two needs that veterans and caregivers have specific to the CSP's PCAFC.

1. **Pass the Veteran Caregiver Re-education, Re-employment, and Retirement Act (S. 3885) that was introduced by Senators Moran and Sinema.** When the original legislation (PL 111-163) was passed creating the VA CSP, the unintended consequence of making the income from PCAFC an unearned income stipend was that 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. Also of note are the few caregivers who only receive CHAMPVA as an insurance benefit through PCAFC lose health insurance within 90 days of leaving PCAFC through the death or discharge of the veteran where, in other insurance programs, members have 180 days to transition other health insurance benefits.

   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 VA in filling gaps in its workforce.

   Lastly, the bill would allow caregivers with CHAMPVA health insurance benefits only through the Caregiver Support Program to keep their health insurance for 180 days rather than the current 90 days. This change would provide much needed equity between ChampVA and other insurance programs.

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 though 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. **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.

   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 any day now. 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.

3. **Remove the language "to the maximum extent possible" when describing the input of the physician in the PCAFC process in the MISSION Act, and add "and relevant medical specialists" after "primary care team" in the section referring to who must give input on a veteran's needs for purposes of the eligibility assessment for PCAFC.** This language is found in the current CARE Act (S1792). A veteran's specialists such as mental health practitioners, neurologists, neuropsychologists, and orthopedists, do not routinely have the ability to directly offer their opinions on the functional ability of a veteran during the PCAFC process. Only PCMs are consulted. Specialists and PCMs have little time to document a veteran's needs, and the criteria for PCAFC are not routine items that a PCM would evaluate. As such, much of the information about very specific treatments or

assistance needs may not be found in the record. PCMs are asked to answer questions about the veteran's treatment plans and institutionalization, but the CSP-PCM PCAFC Collaboration document that is part of the PCAFC application and eligibility process has shown us they rarely answer these questions. PCMs generally do not have time to review all a veteran's specialized treatment plans and, therefore, may answer in a way that disagrees with a specialist who treats a specific, debilitating condition. Local CSP staff normally answer the document assigned for PCMs. By requiring all a veteran's providers to weigh in or document the criteria assessed by PCAFC, we can be assured that medical evidence of a veteran's clinical need is documented by the clinicians who best understand their patient's need(s) for assistance.

Respite Recommendations

In the Fall of 2023, Quality of Life Foundation and the Military Officers Association of America (MOAA) held a joint roundtable with stakeholders in the community which was attended by many VSO groups, bipartisan bicameral Hill staffers from the Committees, White House staffers, non-profit organizations, VACO CSP staff, CMS representatives, TRIWest, and many others. The purpose of the roundtable was to discuss gaps in the respite needs of veterans and caregivers while presenting possible, ACTIONABLE solutions. Of those actionable solutions, we have chosen to highlight three recommendations.

1. **Create a "Pathway to Advocacy" through legislation like the Veteran Caregiver Application and Appeals Reform (CARE) Act of 2023.** As previously stated, this pathway would provide a standardized process for stakeholder organizations to operate on behalf of veterans and caregivers to assist them with navigating various VHA programs. Advocates would be able to provide regular feedback to federal agencies and providers on gaps that exist for veterans and caregivers.

2. **Develop and implement a program of Federal Respite Care Liaisons (FRCL) to assist caregivers with navigating all programs that are available for respite care inter- and intra- federal agencies.** What became abundantly clear at the roundtable was that there are a multitude of programs for respite available in the nation across various agencies, but stakeholders were not familiar with them or did not know how to access them. Creating a Federal Respite Care Liaison (FRCL) to guide caregivers and veterans through all available respite programs across the federal government, modeled on the Federal Recovery Coordination Program (FRCP, in its original intent under the Dole-Shalala Commission), aimed to coordinate all respite care options and help select the most beneficial programs for veterans and their caregivers to use, would allow much better utilization of existing respite programs and prevent caregiver burnout, increasing health outcomes for veterans. Those FRCL's should be located at all VAMCs and at all Programs of All-Inclusive Care for the Elderly (PACE) offices and Area Agencies on Aging offices (state agencies for the elderly). The wide distribution of those FRCL's would allow veterans and caregivers easy access to assistance with finding respite, and the

ability of those FRCLs to recommend respite programs across federal agencies means that veterans and caregivers should be able to access a respite program that meets all of their individualized needs.

3. **Commission a study on caregiver and veteran usage of respite care services across federal agencies and in the community.** At the QoLF-MOAA Respite Roundtable, RAND pointed out that, despite there being a wealth of respite options, caregivers and veterans do not necessarily take advantage of respite care and that there is no data to understand why this occurs. Therefore, before any current changes are made to respite programs, QoLF believes that a study should be performed to understand why caregivers need respite, what barriers exist to using respite, what benefits caregivers receive from respite, and what costs and benefits are associated with respite care usage for all stakeholders. Once the study has collected, analyzed, and finalized data reported, then a better model of respite care services, alongside a menu of respite options that are more user-friendly, can be made available for the population in need of such services.

Conclusion

Quality of Life Foundation appreciates the opportunity to offer recommendations for VHA and for PCAFC. We would like to also praise Dr. Richardson and her VA Caregiver Support Program staff for her continued effort to improve a program that has challenges created by processes established prior to the beginning of her leadership. Thank you for allowing us to submit this testimony for your consideration in continuing to improve PCAFC and VHA overall. We are happy to answer any questions that the Committees have.