

TESTIMONY OF THE ELIZABETH DOLE FOUNDATION
FOR THE SPECIAL COMMITTEE
ON AGING AND VETERANS' AFFAIRS COMMITTEES
HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR
CAREGIVERS

JUNE 5, 2024

Chairmen Casey and Tester, Ranking Members Braun and Moran, and Members of the Committees, thank you for the opportunity to testify today. My name is Meredith Beck, and I am the Senior Policy Advisor for the Elizabeth Dole Foundation (EDF), a national non-profit whose mission is to strengthen, empower, and support America's military and veteran caregivers and their families by raising public awareness, driving research, championing policy, and leading collaborations that make a significant positive impact on their lives. By working with military and veteran caregivers every day through our numerous programs including Hidden Heroes Communities, our Hidden Helpers initiative for caregiver children, the Hope Fund which provides financial relief directly for caregivers, our mental wellness workshops, and through our network of Dole Caregiver Fellows in every state, EDF is keenly aware of and has a unique perspective on the challenges, issues, and remarkable strength of the military and veteran caregiving community we are honored to serve.

U.S. Department of Veterans Affairs Caregiver Support Program/Program of Comprehensive Assistance for Family Caregivers

The U.S. Department of Veterans Affairs (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC) remains a significant concern among all generations of veteran caregivers. We wish to strongly align ourselves with the comments and recommendations made by our partner, the Quality of Life Foundation (QoL), who has clearly articulated the program's current challenges in their written testimony. EDF is proud to sponsor the vital, specialized clinical appeals work done by the QoL. As we await the public release of new regulations governing PCAFC, we look forward to continuing to work with QoL to ensure that veteran caregivers are given the support they need and deserve.

With respect to the new PCAFC regulations, EDF notes that the legacy cohort of eligible caregivers, those post-9/11 veteran caregivers who were admitted to the program prior to September 30, 2020, yet again face an uncertain future. Many of these caregivers have repeatedly been found eligible for the program over the years and endured multiple pauses, regulation and leadership changes, lack of previous program standardization, and questionable assessments. While eligible post-9/11 veteran caregivers have benefitted from the monthly stipend included in the PCAFC, the emotional toil and financial uncertainty caused by programmatic instability in the PCAFC have weighed heavily on caregivers and veterans alike. Therefore, EDF asks Congress to work with relevant veteran service organizations to consider "grandfathering" this population of caregivers into the PCAFC, except in cases of fraud, waste, or abuse. This would allow the Caregiver Support Program (CSP) to focus on its mission of supporting all generations of caregivers rather than continuing this years-long division within the veteran caregiving community.

As the VA works to improve support for veteran caregivers of all generations, we would like to commend the Caregiver Support Program for their efforts to dramatically increase the use of respite care for eligible individuals by over 200% percent through the enactment of “respite champions,” VA employees whose job it is to support access and coordinate services for those seeking to use respite services. Additionally, the recent availability of mental health support for veteran caregivers enrolled in PCAFC has served as a lifeline for many who previously struggled without access to care. While caregiving for a loved one can be incredibly rewarding for the caregiver and often is vital for the well-being of the veteran, the mental health toll on caregivers can be daunting, as has been noted in numerous RAND studies. Therefore, we encourage Congress to broaden access to mental health care for those beyond PCAFC to include those enrolled in the Program of General Caregiver Support Services(PGCSS) under CSP.

Further, we were delighted to learn of the Administration’s FY2025 budget request that included an approximately 20% increase in spending for support and services within CSP. However, we were disappointed to learn recently that, despite the budget request increase and expected program expansion, CSP will not be offered a waiver like other VA programs from the current specific purpose funding restrictions. This means that, in most cases, CSP will not be allowed to hire the front-line social workers, program managers, and nurses that make the program most effective at the local level. This hiring freeze will almost certainly have a detrimental effect on caregivers, veterans, and VA staff who work very hard to support those in the program.

Elizabeth Dole Home Care Act

In addition to CSP, the VA has many programs that, when accessed, benefit veteran caregivers both directly and indirectly, most of which are housed under Geriatric and Extended Care (GEC). At EDF, we see the positive things that can happen when veterans and caregivers are connected by caring, passionate providers and social workers to vital programs and services. Additional respite services, the Veteran Directed, Home-Based Primary Care and the Homemaker Home Health Aide are just some of the programs that support the care and quality of life of veterans and caregivers, especially at home and can serve as a lifeline for veterans and caregivers in need.

Where available, the Veteran Directed Program, for example, has high satisfaction rates among veterans and caregivers across the country. This program, a joint offering from the VA and U.S. Department of Health and Human Services (HHS), offers veterans and caregivers greater choice and control over their care and services by allowing participants to hire familiar friends and family members to provide unskilled care, transportation, skilled care, and other goods and services. Veterans and caregivers can supervise their own employees and hire additional support during the hours that are needed rather than being subject to agency hours and restrictions. In addition, this program has been especially helpful to those who struggle to find appropriate care in their homes either due to contracted agency employee absences or the general dearth of HHA providers around the country as noted in the President’s Executive Order from April 2023.

Unfortunately, despite being created more than sixteen years ago and its demonstrated success, Veteran Directed is still not available in every VA medical center. In many cases, VA staff are unfamiliar with the program even if it is technically available at the facility, or the program exists in name only without the appropriate staff available to ensure its availability and success.

For example, Mary Ward, a Dole Caregiver Fellow, cares for her 100% service-disabled veteran husband and 14-year Amyotrophic lateral sclerosis (ALS) patient, Tom, who receives care from the Durham VA Medical Center. Mary is an astute and effective advocate for Tom. In 2019, once Mary found out another high-need veteran in the area was enrolled in the Veteran Directed Program, she began the process of trying to get Tom enrolled. During the intervening years, she has been told repeatedly that the program was still unavailable in Durham, again, despite knowing another veteran was enrolled. Finally, after significant effort on Mary's part and intervention from EDF, the VA reversed course and Mary was told within the last 2 weeks that the agency would try to enroll Tom in the Veteran Directed Program. If enrolled, Mary will be able to hire her own, familiar home health and respite care support to ensure they are meeting Tom's significant needs.

This process should not and cannot be this difficult for veterans and caregivers. As a result of situations like Mary and Tom's, Ranking Member Moran was joined by Chairman Tester and others to introduce S. 141, *The Elizabeth Dole Home Care Act*. In addition to mandating that every VA medical center provide the Veteran Directed Program, the legislation takes a holistic approach to ensuring this and other GEC programs are offered nationwide and appropriately staffed. The bill also attempts to ensure that caregivers have access to information on available programs and services in a centralized digital location and requires the coordination of other available services if a caregiver is denied or discharged from PCAFC for reasons other than waste, fraud or abuse.

Most notably, the legislation increases the expenditure cap for non-institutional care from 65% to 100% of the cost of the closest VA Community Living Center (CLC). This would allow the most vulnerable veterans and caregivers the support they need to stay in their homes, often leading to better outcomes for veteran families, like the Gareys from Austin, TX. The removal of the cap would help people like Dole Caregiver Fellow Lara Garey, who is present at today's hearing, cared for her 100% service-disabled veteran, Tom, until his death due to complications from ALS in July 2022. Because of the mandated cap, Lara constantly had to fight with the VA to get the appropriate support in their home so Tom could continue to enjoy movie nights with the family, opening gifts on Christmas morning, and even their son's high school graduation, which happened in their living room so Tom could comfortably attend—all of which he would have missed if he were in a facility 2 hours away. It was Tom's greatest wish to remain at home to be surrounded by the peace and love of his family during the hardest of times. Tom deserved to be home with his family, and Lara fought every day to make that possible. As you can see, she continues to advocate on behalf of caregivers and veterans in similar situations.

Eventually, this legislation, which enjoys bipartisan support in both Houses of Congress, was included in its entirety in the recently introduced H.R. 8371, the *Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act*. While the passage of the original Elizabeth Dole Home Care Act is the top priority for EDF, the overall package includes numerous provisions designed to benefit veterans and caregivers including:

- Enhanced access to care in the community for those for whom it has been determined by their clinician to be in their medical best interest.
- Enhanced access to residential rehabilitation for vulnerable veterans.

- Authorizes grants to community-based organizations to provide mental health care to caregivers.
- A long-awaited pilot program to assess the effectiveness of and satisfaction with provided assisted living services.
- Mandates a “Pathway to Advocacy” requiring the Secretary of the VA to develop a process to identify, train, and certify outside organizations to assist veterans and caregivers as they navigate the resources and programs of the Veterans Health Administration.
- Enhanced burial and education benefits for survivors.

Despite strong support from the Chairman and Ranking Members of the Senate Veterans Affairs Committee as well as the Chairman of the House Veterans Affairs Committee, all major veteran service organizations, and disease-related advocacy groups, the legislation has seemingly fallen victim to the politics of the day and been plagued by misinformation and mischaracterization of its provisions. We urge Members of the Senate to reach out to trusted veteran community advocacy organizations to get factual information regarding this legislation to ensure its swift passage, and remove veterans, caregivers, and survivors in need from the political fray.

Additional Issues:

In addition to issues addressed in the *Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act*, EDF would like to highlight other remaining challenges as well as proposals meant to address them.

As noted above, the lack of care coordination especially for those with the most complex needs continues to be an ongoing challenge for veterans and caregivers alike. We regularly hear from caregivers who spend hours every day trying to access the care and benefits their veterans need, to varying degrees of success depending on their knowledge of the available programs and services as well as that of the VA staff with whom they are working. Therefore, EDF supports the following:

- Passage of S. 1792, *The Care Act of 2023* introduced by Chairman Tester and Senator Braun establishing the “Pathway to Advocacy” discussed previously. This legislation would allow knowledgeable organizations to assist veterans and caregivers in the navigation of VA services as well as supplement overwhelmed social workers.
- Discussion and passage of legislation recently introduced by Ranking Member Moran and Senator King, the *Coordinating Care for Senior Veterans and Wounded Warriors Act*. The VA is in the process of implementing its new Care Coordination and Integrated Case Management program which could be helpful for some veterans. For those with the most complex needs, this legislation creates a pilot program to offer a higher level of assistance and is a firm step forward in the establishment of more effective care coordination. We look forward to continuing to work with the Committee on this important issue. Consideration of the amount of demonstrated time a caregiver spends coordinating care for the veteran as part of the PCAFC assessment process. Veterans requiring degrees of supervision and protection are eligible for PCAFC, and ensuring access to health care and services should be a major consideration under this criterion.

- Passage of S. 622, the *Helping Heroes Act*, introduced by Senators Murray and Boozman requiring a full-time Family Support Coordinator at each VA medical Center and requiring the VA to collect data on veteran families to better understand their needs. In the recent past, the VA prioritized the establishment of Family Support Resource Coordinators at each VA medical center, but the position but the position was put on hold as a result of a funding shortfall. These resource coordinators would help connect families and caregivers to the right resources both inside and outside of the VA, potentially providing a longer-term cost savings by proactively connecting families with needed services earlier in their journey.
- The establishment of a case management and social work lead at the VISN level who could help to coordinate training, standardization of services, and serve as a point of contact when challenges arise.

We support all of these initiatives intended to relieve some of the administrative burden for both veterans and caregivers.

With respect to financial wellness, EDF strongly supports two other pieces of legislation intended to alleviate the financial strain often caused by caregiving as well as how to adjust when the caregiving role has concluded due to improvement, death, divorce or other causes:

- S. 3702, the *Credit for Caring Act*, introduced by Senators Bennett and Capito and also endorsed by our partner, AARP, would offer a \$5,000 tax credit to eligible working family caregivers, both veteran and civilian, to offset the over \$7,200 in out-of-pocket caregiving expenses incurred every year. This legislation would clearly remove some of the financial strain experienced by these families, especially those veterans who are either not associated with the VA or have experienced the difficulty discussed above accessing the programs and services available to them and, instead, pay out of pocket for their needed goods and services.
- S.3885, *The Veteran Caregiver Reeducation, Reemployment, and Retirement Act* introduced by Ranking Member Moran and Senator Sinema. For many PCAFC caregivers, their caregiving role will come to an end, hopefully due to improvement in the veteran for whom they care, but any number of reasons can be cited for this outcome. This legislation would do many things to alleviate that anxiety including extend enrollment in the Civilian Health and Medical Program of the Department of Veterans Affairs(CHAMPVA) for up to 180 days after disenrollment from PCAFC, allow the VA to pay caregivers up to \$1,000 to maintain professional licensure, study the feasibility of establishing a retirement plan for family caregivers, and study the barriers and incentives to hiring former family caregivers to work for the VA.

While EDF strongly endorses this legislation, we would also suggest an amendment to help alleviate a current inequity related to retirement planning for parents enrolled in PCAFC who care for their service-disabled child, currently approximately 2,500 individuals. The VA offers a program called Dependency and Indemnity Compensation, a monthly tax-free monetary benefit offered to eligible survivors—this program is often a financial lifeline for those who are eligible, and spouse survivors are rightfully not subject to an income threshold. Parent caregivers, however, are subject to an income

threshold, in some cases as low as approximately \$18,000/year. For example, EDF is familiar with a parent caregiver in Florida whose combat-injured Marine son recently passed away. His single mother was his caregiver for 17 years following his severe injuries, and now at age 73, she is unable to return to work. Because she is a parent, she is subject to the DIC income limit, and her \$23,000 annual social security payment exceeds the threshold. With Social Security now her sole source of income, she is in danger of losing the home she shared with her son after his injury.

As the Committee considers S. 3885, EDF requests that the Committee consider abolishing or greatly increasing the DIC income limits for non-spouse caregivers enrolled in PCAFC, allowing them to plan for retirement and leaving them far less financially vulnerable when their caregiving role has concluded.

Conclusion:

While caregivers and veterans still face significant challenges today, many can be addressed through continued oversight and the legislative initiatives mentioned above. Specifically, the *Elizabeth Dole Home Care Act* as well as the language included in the larger legislative package would provide, in many cases, immediate relief to those caregivers and veterans most in need. Therefore, the Elizabeth Dole Foundation calls on Congress to come together, treat this vital legislation with the respect and urgency it deserves, and pass it without delay. Veterans and caregivers cannot wait any longer for its life-changing, and likely life-saving provisions.

Thank you, Mr. Chairmen, and I look forward to your questions.

