

WRITTEN TESTIMONY

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THE ELIZABETH DOLE FOUNDATION
BEFORE THE HOUSE VETERANS AFFAIRS COMMITTEE

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Introduction

Chairman Bost, Ranking Member Takano, and Members of the Committee, thank you for the opportunity to testify today. My name is Steve Schwab, and I am the CEO of the Elizabeth Dole Foundation (EDF), a national non-profit whose mission is to strengthen and support military and veteran caregivers, founded on the legacy and service of Senator Elizabeth Dole.

Before I begin, I want to recognize the more than 60 Dole Caregiver Fellows we have in attendance today, as well as many more watching online. They have taken precious time away from their caregiving duties to watch and be here and will be visiting your offices this afternoon sharing their message of hope and calls to action for all Members of Congress. These caregivers provide a tremendous economic value, approximately \$119 Billion at a minimum, according to the newly released RAND study. Beyond their economic value and even more importantly, they promote better outcomes for veterans, options for care both in and outside of the home, family cohesion, and community involvement. Simply put, their value to their loved ones cannot be overstated.

In addition, given that so many of our caregivers will transition to veteran survivors, I also want to recognize that this is Gold Star Families Remembrance Week. In many ways, these caregivers and survivors have “borne the battle” mentioned in President Lincoln’s speech and deserve all of the honor and support this nation can offer.

Yesterday, the Elizabeth Dole Foundation was pleased to welcome over 600 guests to our 9th Annual Convening launching the RAND study outlined by Dr. Ramchand in his testimony. This landmark study, released 10 years after the initial RAND report outlining challenges in military and veteran caregiver community, reflects what we see every day at EDF as well as in the moving testimony from our Dole Fellow, Vanessa Chism. We could not be more proud of her and her family for being willing to share their experiences to help others.

In reviewing the new RAND report and considering our own everyday experiences with military and veteran caregivers, we have coalesced around four interconnected areas of focus, which will guide our programmatic and advocacy efforts moving forward.

Economic Mobility:

As Dr. Ramchand testified, the RAND report identified multiple factors influencing the economic stability of caregivers. Lost wages, inability to plan or save for retirement, unforeseen out of pocket expenses, and unemployment because of caregiving duties all often result in financial strain and uncertainty on caregiving families. Family members often leave jobs to care for a loved one and can no longer contribute to retirement plans and lose valuable professional credentials over time. They also often find that their employers simply do not recognize the reality of life at home or give them the support they need, like paid family leave. We are proud to be able to provide Emergency Financial Relief through our Hope Fund supported by the Bob and Delores Hope Foundation, but we must do more. We must give caregivers and their families the opportunity to achieve not only short-term economic stability, but also long-term economic mobility to ensure the hope of a better life for generations to come. Fortunately, there are several actions Congress can take to address this and other situations to relieve some of the financial burden facing these caregivers:

First, Congress must demand the immediate publication of the Notice of Proposed Rulemaking (NPRM) regarding the VA's Program of Comprehensive Assistance for Family Caregivers. (PCAFC). This program, which provides vital financial and other support to those caring for veterans with the most complex needs, has been an economic lifeline. However, since March of 2022, the program has been on hold while the VA reviewed concerns related to its eligibility criteria. While we applaud the VA for recognizing and working to address the concerns, the agency and Administration have been working on an NPRM for almost 2 years, leaving those impacted in significant financial limbo. Numerous organizations, including EDF, recently sent a letter to the President requesting the publication of the proposed rule, and we would welcome Congress' oversight on this issue.

In addition, EDF requests that consideration be given to 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.

With respect to the legacy cohort of PCAFC participants, those Post-9/11 caregivers who were admitted to the program prior to September 30, 2020, yet again face an uncertain future due to the pending

changes in eligibility requirements. 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 they have benefitted from the stipend, the emotional toil and financial uncertainty have weighed heavily on caregivers and veterans alike.

Therefore, EDF asks Congress to work with the VA and relevant veteran service organizations to consider “grandfathering” this population of approximately 14,000 caregivers into PCAFC, except in cases of fraud or abuse, and allow the VA’s Caregiver Support Program (CSP) to focus on its mission of supporting all generations of caregivers, rather than continuing this year's long struggle.

With respect to legislation that would positively impact the economic mobility of family caregivers, EDF endorses the following:

- H.R. 7165/S. 3702, the *Credit for Caring Act*, introduced by Congressman Mike Carey and Congresswoman Linda Sanchez, and endorsed by our partner, AARP, which would offer a \$5,000 tax credit to eligible working family caregivers, both veteran and civilian, to offset the over \$8,500 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 difficulty accessing the programs and services available to them and, instead, pay out of pocket for their needed goods and services.
- H.R. 9276/S.3885, *The Veteran Caregiver Reeducation, Reemployment, and Retirement Act* introduced by Congressmen Morelle and Ciscomani. For many enrolled in PCAFC, their caregiving role will come to an end, hopefully due to improvement in the veteran for whom they care, but, sadly, often due to the passing of the veteran. This legislation would do many things to alleviate the caregiver’s financial strain and 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 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, Christine

Cooley of Florida cared for her severely combat-injured Marine son, Josh, until he passed away last October. As a single mother, she was his caregiver for 17 years following his severe injuries. 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 Congress considers H.R. 9276, EDF requests that the Committee consider abolishing or greatly increasing the DIC income limits for non-spouse caregivers enrolled in PCAFC, currently approximately 18,000 caregivers, allowing them to plan for retirement and leaving them far less financially vulnerable when their caregiving roles come to an end.

- H.R. 3651, the *Love Lives on Act of 2023* introduced by Congressmen Dean Phillips and Richard Hudson. As I mentioned previously, military and veteran caregivers often become survivors, and many caregivers we encounter have significant concerns about what happens to them financially if/when the veteran passes away. In addition to the grief they experience, they also can experience benefit loss. Among other things, the legislation would allow surviving spouses to retain the Survivor Benefit Plan (SBP) and Dependency and Indemnity Compensation (DIC) upon remarriage at any age and allow surviving spouses to maintain eligibility for education benefits under the Fry Scholarship and Dependents Education Assistance upon remarriage or if that marriage subsequently ends due to death, divorce, or annulment. Finally, it allows remarried surviving spouses to regain their TRICARE benefits if that marriage subsequently ends due to death, divorce, or annulment.

Mental Health and Wellness

The second and third focus areas identified by EDF through the findings in the RAND report are a need to support the mental health and wellness of the caregiver and to address the unique needs of children in the caregiving home.

As Dr. Ramchand noted in his report, the mental health toll on family caregivers is tremendous, with 43% of those caring for a veteran under the age of 60 meeting the criteria for depression, and a staggering 22% of that same population reporting suicide ideation. Thirty-six percent of those caregivers wanted mental health treatment but did not get it, mostly because they lacked the time to do so or feared how being hospitalized or taking medication would impact their ability to care for their loved one. The good news is that we, as a society, have raised awareness of the need to identify mental health needs. Now we need to identify ways to address them more easily.

At the same time, 27% of military and veteran caregivers are also raising a child, and 39% of those children help with at least one caregiving task. It is important to note that, in addition to assisting with activities of daily living like administering medication and feeding, young children are also learning to modify their behavior to avoid “triggering” a parent or, like Vanessa said, for those with cognitive issues, learning to remind their dad why he is at the grocery store. Supporting these families and ensuring safe households for veterans and their families is not only the right thing to do; it is also the smart thing to do, as many of these children often grow up with a desire to serve in the military themselves.

Keeping this data in mind and to ensure better outcomes for caregivers, the veteran, and the entire family, the Elizabeth Dole Foundation recommends and endorses the following:

- *Expand Access to mental health care beyond those enrolled in PCAFC.* 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 above. Therefore, we encourage Congress to, at a minimum, 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.
- H.R. 3581 the *Caregiver Outreach and Program Enhancement (COPE) Act*, introduced by Congresswomen Jen Kiggans and Chrissy Houlahan, would improve access to mental health support for veteran caregivers by establishing grant programs that support their overall mental health and well-being. This type of support serves the caregiver and the veteran for whom they are providing care by addressing the stress, anxiety, and depression that can be associated with caregiving. It also gives options to caregivers who may not be comfortable or eligible to get services through the VA. While this legislation has passed in the House of Representatives, we strongly support its final passage in both Houses of Congress.
- H.R. 8165, the *VA Marriage and Family Therapists Equity Act*, introduced by Congresswoman Julia Brownley, would expand access to professional therapists for caregivers and veterans by removing an outdated licensing requirement that limits the availability of appropriate qualified therapists. Due to the nature of caregiving and the general stress on families today, EDF is seeing, anecdotally, a significant increase in the number of marriages, families, and children that need support. This legislation would go a long way toward addressing the availability of needed therapists.

- Identify/Develop a scale to accurately measure the caregiving intensity of those caring for individuals with mental health and cognitive disorders. The RAND report notes that while scales exist to measure caregiver intensity, they may be biased in how they are constructed by assigning higher intensity levels to those providing support with Activities of Daily Living, such as helping care recipients bathe or dress, versus those caring for individuals with mental health and cognitive deficits. Given that the report also cites a higher incidence of mental health and cognitive issues for care recipients under the age of 60, as well as a higher incidence of mental health needs among their caregivers, it is important that a scale be developed to accurately measure their caregiving intensity, so we may better understand and attend to their needs.

Improving the Care Ecosystem for Veterans and their Caregivers

Given the expansive nature of RAND's report, as well as our daily experience with caregivers, the fourth focus area identified by EDF is the need to Improve the Care Ecosystem for Veterans and their caregivers to ensure the remaining needs of this population were captured. This broadly encompassing area includes a focus on improvement and increased access to programs and services that enhance and promote both the veteran and caregiver's whole health. EDF notes that, while potentially eligible, veterans and their caregivers must navigate a complex array of benefits and services to find the right "Easter Egg" and often are not aware of programs that could benefit them. In addition, there are gaps and outdated restrictions on many programs that limit access to those in need. The near constant effort to identify resources and advocate on behalf of the veteran can weigh heavily on both the caregiver and veteran.

In recognition of this struggle and the effort to improve the care ecosystem in the clinical setting, in the home, and in the community, EDF recommends the following:

- *Addressing the current Veterans Health Administration(VHA) Budget Shortfall.* While we appreciate that Congress acted quickly to address the funding shortfall for the Veterans Benefits Administration, the challenge remains to fund VHA at appropriate levels to ensure veterans and their caregivers receive needed and earned care and services. While the Caregiver Support Program is a small part of the VA, the impact of the shortfall on this program shows the overall impact at the operational level for veterans and their caregivers. Abolishing front line positions to disguise need, hiring freezes, a lack of clinical providers and social workers, and budget cuts to vital programs like respite that were just finally gaining traction, endangers veterans and caregivers.

In addition, prior to the identification and announcement of the shortfall, multiple new programs impacting veterans, caregivers, and survivors were on track for full implementation. The Family Resource Coordination Program intended to connect families with needed services both inside the VA and in the community to prevent many of the issues we have heard about today has now gone from a phased implementation plan at each VA Medical Center with a full-time dedicated employee to a pilot program. This will certainly delay access to this service for many caregivers and families in need. The Survivor Assistance and Memorial Affairs program housed under VHA is designed to offer personalized supportive services to families, caregivers, and survivors at the end of a veteran's life is now unable to move forward as planned at each VA medical center. Lastly, the establishment of a lead social worker at the VISN level to standardize services, establish training protocols and serve as a point of contact for exceptionally complex cases was put on hold. All these programs and services are intended to connect caregivers and families with resources before a crisis occurs and could potentially promote cost savings in addition to the added peace of mind for the

- *Expansion and Further Adoption of the Campaign for Inclusive Care.* EDF partnered with the VA to train clinicians and staff on the practice of inclusive care through our Campaign for Inclusive Care. The program is intended to improve the health outcomes for the veteran, reduce the stress and burden on the caregiver, and reduce burnout on the part of providers because of more effective visits. CIC also shows promise in reducing VA costs by minimizing ER visits and increasing medication adherence, promoting better outcomes for the veteran and family. The program has been well received and veterans and caregivers would benefit from its further expansion
- Passage of H.R. 4518, *The Care Act of 2023* introduced by Chairman Tester and Senator Braun establishing the "Pathway to Advocacy". This legislation would allow knowledgeable organizations to assist veterans and caregivers in navigating VA services and supplement overwhelmed social workers.
- Discussion and passage of H.R. 9399, the *Coordinating Care for Senior Veterans and Wounded Warriors Act* recently introduced by Congressmen Morelle and Ciscomani. The VA is 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.
- *Passage of H.R. 542, the Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act of 2023*, introduced by Congresswoman Julia Brownley and modified favorably in the Senate. In addition to the Caregiver Support Program, the VA has many programs that, if

accessed, benefit caregivers both directly and indirectly, most of which are housed under Geriatric and Extended Care (GEC). At EDF, we see and hear about 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 their care and their quality of life. Additional respite services, Veteran Directed Care, Home-Based Primary Care, and the Homemaker Home Health Aide 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. Where available, the Veteran Directed program, for example, has incredibly high satisfaction rates. The program, a joint offering from the VA and the Department of Health and Human Services, offers veterans and caregivers greater choice and control over their care and services. They can use the program to hire familiar friends and family to provide unskilled care—especially important to those with mental health needs and traumatic brain injuries—transportation, skilled care, and other goods and services. They can supervise their own employees and hire support during the hours that are needed, rather than being held subject to agency hours and restrictions. In addition, this program has been incredibly helpful to those who struggle with getting 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 April 2023 Executive Order, *Increasing Access to High Quality Care and Supporting Caregivers*. Unfortunately, despite being created in 2008 and demonstrating success since then, 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 supposedly 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 ALS patient, Tom, who receives care from the Durham VA Medical Center. Mary is an astute and effective advocate for Tom. In 2019, once she 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. However, over the intervening years, she has been told repeatedly that the program was still unavailable in Durham, a large VA medical center—again, even though another veteran was already enrolled. Finally, after significant effort on Mary’s part and intervention from EDF, the VA reversed course and Mary was told recently that the agency would try to enroll Mr. Ward in an existing area of coverage for the Veteran Directed Program. If enrolled, Mary will be able to hire her own home health and respite care to ensure Tom’s needs are met. This should not and cannot be this difficult for veterans and caregivers.

As a result of situations like Mary and Tom’s, Congresswoman Brownley thankfully introduced the *The Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act*.

In addition to mandating that every VA medical center provides the Veteran Directed Program, the legislation, as modified in the Senate, takes a holistic approach to ensuring this and other GEC programs and services are offered and appropriately staffed. It also attempts to ensure that caregivers have access to information on available programs and services in a centralized 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 allows the most vulnerable veterans and caregivers the support they need to stay in their homes, often leading to better outcomes for the family. The removal of the cap would have helped people like Dole Fellow Lara Garey from Austin, TX, who cared for her 100% service-disabled veteran, Tom, until his death 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, attending concerts, and even being present for their son's high school graduation—all of which he would have missed if he were in a facility 2 hours away. It was Tom's greatest wish to remain in their home and maintain as normal a life as possible in such an abnormal situation. He wanted to be surrounded by the peace and love of his family during the hardest of times. He deserved that choice, and Lara fought every day until his death to make that possible.

Rapid, Thoughtful Expansion of the Veteran Directed Respite Pilot. As the VA works to improve support for veteran caregivers of all generations, we would like to commend the Caregiver Support Program for its efforts to dramatically increase the use of traditional respite care for eligible individuals by over 200% 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. In addition, the VA has recently launched a pilot program in 10 sites providing access to respite care through the Veteran Directed program, allowing caregivers and veterans the ability to hire their own respite services. This is especially beneficial for those with specialized needs, including severe mental health and cognitive disorders, as they can hire and hire providers familiar to them during the hours of their choosing.

Call to Action

Fortunately, many of the pieces of legislation mentioned above, the *Elizabeth Dole Home Care Act*, the *COPE Act*, *The Care Act of 2023*, and the *Love Lives On Act* were included in H.R.8371, the *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, to which Senator Dole was also proud to lend her name, includes numerous additional 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.
- A long-awaited pilot program to assess the effectiveness of and satisfaction with assisted living services, giving veterans and caregivers options in their care.
- Enhanced burial and education benefits for survivors.

Conclusion:

At the Elizabeth Dole Foundation, we focus on issues that directly impact caregivers and issues of significant interest to them. Many of the challenges outlined here and in the RAND report can be addressed through continued oversight and the legislative initiatives mentioned above. Specifically, the *Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act*, which enjoys strong support from all major veteran service organizations, would provide, in many cases, immediate relief to those in need. We urge Members of the House to reach out to trusted veteran, caregiver, and survivor advocacy organizations to hear their perspective on this legislation and then ensure its swift passage. Veterans and caregivers have been waiting for two years for Congress to take action on many of the provisions in the bill, and they simply cannot wait any longer for its life-changing, and likely life-saving provisions.

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