

**WRITTEN TESTIMONY OF STEVE SCHWAB,
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BEFORE THE HOUSE COMMITTEE ON VETERANS' AFFAIRS SUBCOMMITTEE
ON HEALTH, UNITED STATES HOUSE OF REPRESENTATIVES
ON ELIZABETH DOLE HOME AND COMMUNITY BASED SERVICES FOR
VETERANS AND CAREGIVERS ACT OF 2022**

March 16, 2022

Chairwoman Brownley, Ranking Member Bergman, and Members of the Subcommittee, on behalf of the Elizabeth Dole Foundation, I am pleased to testify on the *Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act*.

The Elizabeth Dole Act is named for a revered public servant who has devoted her life to building coalitions of Americans to solve our nation's greatest challenges.

Fittingly, the bill is a true reflection of Senator Dole's legacy. It helps uphold the promise our nation makes to the military families bearing the wounds and illnesses of war. And it is precisely focused on providing *solutions*—solutions that are worthy of bipartisan support and that will directly address the most common and persistent hardships of our veterans, their families, and their caregivers.

In the ten years since the Elizabeth Dole Foundation was established, we have commissioned consequential and groundbreaking research on military caregivers, veterans, and their families. We have also grown the most active and trusted network of caregivers and their supporters in the nation. The Elizabeth Dole Act addresses key systemic issues we have chronicled through our work, both anecdotally and through evidence-based studies.

The Elizabeth Dole Act reinvests in caregiver support at the U.S. Department of Veterans Affairs (VA), establishes a user-friendly resource center, and expands VA Home-Based Community Services nationwide. This legislation provides greater access to resources and helps to determine which services provide optimal support for the caregiver and their family as they navigate a complex web of available help. We are proud to support this transformational legislation.

We know that right now, thousands of caregivers are being transitioned out of the Program of Comprehensive Assistance for Family Caregivers (PCAFC) since last fall, due in part to the expansion of PCAFC services to pre-9/11 caregivers. This transition means the loss of financial support, access to crucial mental and emotional health services, and other key benefits to post-

9/11 caregivers. There is a lot of discussion surrounding whether this is the right path forward, but I want to make one thing absolutely clear—**PCAFC should not be seen as the sole program providing caregiver supports at the VA.** This legislation aims to flip the perception of caregiver services on its head, bolster and expand the programs that are better suited for these families and lessen the pressure of being accepted into PCAFC.

Among its many provisions, this legislation will reinvest in caregiver support at the U.S. Department of Veterans Affairs, expand VA Home and Community-Based Services, provide greater access to critical resources, and help caregivers determine which services are available and right for them.

EDF has long advocated for **the enhanced improvement of the transition of caregivers who are either ineligible for or were discharged from PCAFC and establish optional enrollment in the Program of General Caregiver Support Services (PGCSS).** In the fall of 2021, the VA’s Federal Advisory Committee on Veterans’ Families, Caregivers, and Survivors, chaired by Elizabeth Dole, approved a [recommendation](#) that asked the VA to “present a plan for how it intends to regularly outreach and explain criteria to potential applicants to the Program of Comprehensive Assistance for Family Caregivers.” This recommendation also asked the VA to “develop material to send to those who have been denied from the program that includes information on the Program of General Caregiver Support Services (PGCSS), the Respite Relief Program, and any other resources that are available.” Lastly, the recommendation suggested that “the application for PGCSS should be concurrent with the application for PCAFC and allow family members to apply for both programs simultaneously.”

Section 5 of the Elizabeth Dole Act and this recommendation from the Federal Advisory Committee targets an issue that has been impacting caregivers and their families and unfortunately has mostly gone unnoticed. Even though the VA has other programs that provide support for caregivers, such as PGCSS, PCAFC has ultimately overshadowed these offerings. PCAFC was not designed to support all the 5.5 million military and veteran caregivers around the country. Additionally, as this Congress knows, many post-9/11 caregivers are receiving notification that they will be transitioned from PCAFC. The process by the VA to reassess eligibility of post-9/11 caregivers for PCAFC has both frustrated and exhausted caregivers and their veterans. The prospect of initiating another application for PGCSS feels unduly burdensome to America’s veterans and their caregivers. By giving PCAFC applicants the ability to enroll in PGCSS simultaneously using the same evaluation, the VA could streamline its process for caregiver support and ease the perception that PCAFC is the only support service of any value available from the VA. Additionally, participation in PCAFC has unintentionally become tied to one’s standing as a caregiver. This was not the intention, yet the Foundation has noted a common perception among caregivers that if one is in the PCAFC, your status as a caregiver is more “important.” As the Foundation has said time and time again, **identity as a**

caregiver is not defined by enrollment in any VA, government, or nonprofit program.

Caregiving is a selfless mission of love and devotion, and a service to this nation. No person, entity, or organization can take that away.

This section also **requires the development of a standardized administrative assessment tool to help assess the needs of the family and recommend specific Home and Community-Based Services.** This provision is an effort to improve the user experience and streamline the process of searching for additional resources. If these programs are asking the same administrative questions and collecting similar information, it seems plausible that this same information might be used to inform veterans and caregivers of possible eligibility in other VA programs. By doing so, the VA can provide families with alternative resources beyond PCAFC.

Section 6 of the legislation calls for a creation of a “**centralized and publicly accessible internet website of the Department as a clearinghouse for information and resources**”. This digital hub could become a go-to offering by the VA. The VA has many great programs and resources, but few users know about them. Additionally, they are dispersed across multiple departments and program pages, making them increasingly difficult to find. Creating a one-stop shop of VA resources for families would be vital to their support. Allowing families to enter information about their needs and receive recommendations for resources would ensure that these programs are accessible and being fully utilized.

The Foundation would also like to take the opportunity to highlight Section 4 of the legislation that **expands VA Home-Based Community Services and leverages caregiver-inclusive language.** This point on caregiver-inclusive language is a small change that would have a major impact on the community. The legislation calls for annual wellness checks to be conducted on caregivers whose veterans are participating in Veteran-Directed Care, Home Maker and Home Health Aide program, Home-Based Primary Care program, and the Purchased Skilled Home Care program.

We have received feedback from our community that PCAFC is often the only time when the VA is specifically checking in and connecting with the caregiver. Other programs that have VA staff entering the home, such as the programs within the section, provide a quintessential opportunity for staff to also conduct checks to the caregiver and get a sense of their needs and wellbeing. The Foundation would also like to ensure that this expands to PGCSS as well. This inclusion and recognition of the caregiver and their needs is invaluable, especially when we know that caregivers experience higher rates of isolation, anxiety, and burnout when compared to their peers. The complicated, all-consuming pressure that comes with caregiving is enormous. And for military and veteran caregivers who often assist care recipients with complex invisible wounds, the toll it takes on their own emotional well-being is far higher.

In a recent pulse check survey of the Hidden Heroes network conducted by the Elizabeth Dole Foundation, many caregivers shared with us how much they appreciated and valued their local caregiver office and their caregiver support program staff. We want to encourage these organic relationships and help families build that strong communication and connection with their local VA staff. This crucial lifeline should not be contingent on PCAFC enrollment, and this section is instrumental in addressing this issue.

In Section 8, the Elizabeth Dole Act looks to the future and proposes a framework for resources to come. Along with the VA conducting a **review of the programs administered by the Office of Geriatric and Extended Care and the incentives of administering Home-Based Community Services**, the legislation also requires a **review of respite and mental health services**.

Removal from PCAFC isn't always about the financial benefit. Enrollment in PCAFC opens access to other VA programs like respite care and take some time for themselves. At EDF, we know just how important it is for caregivers to take a break. At the onset of the pandemic, it was the primary need within our community. This led to the creation of our Respite Relief Program which partners with the VA. The impact that just four hours of respite had on participants was astonishing.

Through our pre- and post-service surveys, we have been able to track the tremendous impact this program is having on military and veteran caregivers, their wounded warriors, and their families. There is a real demonstrated need for assistance with daily caregiving responsibilities, and there is a significant (positive) impact on the mental health of caregivers after they receive their allotted respite hours.

In our pre-service survey, 44.13% of caregivers rated their health as good to excellent. After receiving respite relief, 92.4% of caregivers rated their health as good to excellent. We are seeing a 48.27 point or more than 100% increase in how caregivers feel after just a few hours of respite relief.

PCAFC also offers caregivers and their families opportunities for mental health services. Many of our caregivers have greatly benefited from receiving these services, including marriage counseling and group therapy. By conducting a review and expanding opportunities for mental health services across the VA, this change would drastically benefit those being denied or discharged from PCAFC.

Finally, our Foundation was encouraged to see this legislation call for **enhanced coordination between the VA, nonprofits, and Veteran Service Organizations**. Today's VA has been the most forward-leaning in its investment and recognition of military and veteran caregivers. However, we know that the VA cannot do it alone. Our Foundation will proudly continue our work with the VA, which has already produced reforms and services that have been transformative to the caregiver experience, and we look forward to what the future brings.

We were honored and humbled when Chairwoman Brownley asked to name this legislation after Senator Dole. She was moved beyond words and grateful that this committee is recognizing the vital role that Hidden Heroes play in the care of America's veterans. We strongly encourage those on this committee to support this bill and ask your colleagues to vote to enact it into law.