

**WRITTEN STATEMENT OF STEVE SCHWAB,
CHIEF EXECUTIVE OFFICER OF THE ELIZABETH DOLE FOUNDATION
BEFORE THE SENATE VETERANS' AFFAIRS COMMITTEE,
UNITED STATES SENATE ON
2018 MISSION ACT, TITLE 1 IMPLEMENTATION**

October 21, 2020

Chairman Moran, Ranking Member Tester, and Members of the Committee, the Elizabeth Dole Foundation is pleased to testify today on the expansion of the VA Program of Comprehensive Assistance for Family Caregivers. Hundreds of thousands of military caregivers are counting on us to get this expansion right, as are the generations of veterans who depend on their care.

The original legislation establishing this program unfairly drew an artificial line between the caregivers of those who served before September 11, 2001, and those who followed them. Our nation must continue to swiftly act to end this disparity in caregiver benefits.

Pre-9/11 caregivers provide a tremendous service on behalf of our nation, and it exacts an enormous toll on their lives. In 2014, the Elizabeth Dole Foundation released a landmark study by the RAND Corporation that found:

- Ten percent of pre-9/11 caregivers spend more than 40 hours per week providing care.
- A quarter have taken unpaid time off from work or temporarily stopped working because of their caregiving. More than 13 percent have dropped out of the workforce entirely.
- The most common pre-9/11 caregiver is a grown child of the veteran. Many of these caregivers fall in the “sandwich generation” who simultaneously care for their parent and children.

These hidden heroes are an unpaid workforce contributing nearly \$15 billion in care every year—the vast majority of which is provided by pre-9/11 caregivers. And, experts agree that a well-supported caregiver is the most important factor to the well-being of a veteran.

Correcting the inequity of caregiver benefits was one of our Foundation’s first and most urgent priorities. We applaud Congress for responding to our call, and we are grateful that Secretary Robert Wilkie and the U.S. Department of Veterans Affairs have carried out this legislation as part of the VA’s continued investment in caregivers.

Unfortunately, implementation of the expansion has been marred by ambiguities and delays that have led to widespread frustration and confusion among the caregiver population.

Our chief concern is the pace of implementation. After more than a year of delays, the VA still intends to roll-out benefits in protracted phases, requiring those caring for veterans who served

after May 7, 1975 to wait two more years for eligibility. We understand the phased approach is specified by law, but these prolonged delays are further straining caregivers. The VA's *Veterans' Families, Caregivers and Survivors Federal Advisory Committee*, chaired by my boss Senator Elizabeth Dole, recently recommended that Congress provide legislative relief to expedite this timeline. Mr. Chairman, Senator Tester...Senator Dole hopes action is taken on this very important recommendation. And even more important, our pre-9/11 caregivers who are being forced to wait even longer to receive their benefits hope you take action immediately.

Our Foundation also strongly urges the VA to standardize the expansion's implementation. The largest source of caregiver anxiety and dissatisfaction with the PCAFC has always been the inconsistencies between VA centers. Among the areas open to interpretation is the requirement for annual assessments. Some medical centers choose to evaluate caregivers multiple times each year, which causes undue stress among these caregivers over the possibility that they will be dropped from the program.

Additionally, key language about how caregivers are evaluated lacks clarity. We are particularly concerned about the reliance on Activities of Daily Living as the marker for how much care a veteran requires. Mandating that caregivers assist with ADLs on a "daily basis" or "each time they are performed" will likely disqualify those caring for veterans with post-traumatic stress and traumatic brain injury. The abilities of veterans with cognitive injuries can vary over time, even hour-by-hour. We cannot leave their caregivers unsupported.

At the core of the implementation's challenges is a critical lack of communication. Caregivers have largely learned that the program was officially expanding benefits on October 1st second-hand, through social media and word of mouth. However, large percentages of the caregiver population do not use social media or participate in online communities. Furthermore, those who do participate in these communities are vulnerable to inaccurate information. The VA must invest in a proactive, comprehensive communications campaign to ensure all caregivers receive the benefits they critically need and deserve.

Finally, our Foundation calls on the VA to create a permanent head of the VA caregiver support program and classify the position as an SES. A program of such importance requires an established position of senior leadership.

While we strongly encourage the VA to respond to the recommendations we have presented today, we also praise the Department for its commitment to implementing this historic legislation. We know it is a tremendous task. The Elizabeth Dole Foundation and our coalition of partners are standing by to assist in promoting the program—if the VA should ask.

Thank you again for this opportunity to appear before you today. We look forward to continuing to work together to support our nation's veteran caregivers.