

**STATEMENT FOR THE RECORD  
ELIZABETH DOLE FOUNDATION  
FOR THE HOUSE COMMITTEE ON VETERANS' AFFAIRS LEGISLATIVE HEARING  
MARCH 29, 2023**

Chairman Bost, Ranking Member Takano, and Members of the Committee, thank you for the opportunity to provide a written statement for today's hearing. Today's docket consists of a series of legislation for your consideration, and we would like to focus our attention on one: *The Elizabeth Dole Home Care Act*.

As you may know, the Elizabeth Dole Foundation is the preeminent organization empowering, supporting, and honoring our nation's military caregivers; the spouses, parents, family members and friends who care for America's wounded, ill or injured veterans. The Foundation was born out of Senator Elizabeth Dole's conversations with caregivers while Senator Bob Dole was receiving care at Walter Reed Medical Center, and she realized that not enough was being done for military and veteran caregivers. Senator Elizabeth has since made the transition from caregiver to survivor after the passing of Senator Bob in 2021, but she remains steadfast and fervent in her advocacy on behalf of caregivers.

*The Elizabeth Dole Home Care Act* is critically important to military and veteran caregivers across the nation. This legislation was first introduced in both the House and Senate during the 117<sup>th</sup> Congress. It received bipartisan support and endorsed by a diverse coalition of organizations, including Paralyzed Veterans of America, The American Legion, AARP, Disabled American Veterans, Wounded Warrior Project, Veterans of Foreign Wars, National PACE Association, National Council on Urban Indian Health, and the National Association of Counties.

This bill is an investment in resources that help veterans age in place and could not come at a more appropriate time. In 2014, [research conducted by RAND](#) and commissioned by the Elizabeth Dole Foundation found that there are approximately 5.5 million military and veteran caregivers in the United States that provide \$14 billion annually in unpaid labor, caring at home for their veteran loved ones. With inflation, this equates to approximately \$20 billion today. [Experts predict](#) that by 2050, there will be an estimated 1.5 billion people aged 65+ worldwide, which is a sharp increase from 703 million in 2019. Not only are people living longer, but they are more likely to have chronic health conditions that require regular care. A [study conducted by AARP](#) found that 76% of people aged 50 or older would prefer to remain in their current home for as long as possible. These trends all point to the ever-growing need to invest in home and community-based services and the caregivers who step into this role.

The version of *The Elizabeth Dole Home Care Act* [as introduced during the 117<sup>th</sup> Congress](#) included the following provisions:

- Increase the non-institutional expenditure cap from 65% to 100%.
- Expedite and expand access to the Department of Veterans Affairs (VA) Home and Community-Based Services (HCBS) to all Medical Centers, including those in the U.S. territories, in two years. Services include:
  - The Veteran Directed Care Program – Provides veterans a flexible budget to hire friends, family, and neighbors to help with activities of daily living.
  - The Home Maker Home Health Aide Program – Allows VA to contract with a community partner that employs home health aides to care for veterans in their homes.
  - The Home-Based Primary Care Program – For a veteran who has difficulty traveling, is isolated, or whose caregiver is burdened, a VA physician will supervise healthcare in the veteran's home.

- The Purchased Skilled Home Care Program – For veterans who have higher levels of need the VA will contract with a community agency to provide skilled nursing care in a veteran’s home.
- Require VA to continue working with caregivers if they are denied from a program to find an alternative. VA must inform caregivers of other services they can access and ensure they are connected to appropriate resources.
- Expand access to respite care for family caregivers of veterans enrolled in home care programs.
- Establish a “one stop shop” webpage to centralize information for families and veterans on all programs and includes an informational eligibility assessment tool.
- Mandate stronger coordination between the Program of Comprehensive Assistance for Family Caregivers (PCAFC) and VA’s other services. If a veteran is denied or discharged from PCAFC, the veteran must be assessed for participation in all other HCBS programs.
- Establish a three-year pilot program to address shortages of home health aides. VA will directly hire or repurpose current nursing assistants to be home health aides for veterans.

Last winter, the Congressional Budget Office (CBO) [published their cost estimate](#) for *The Elizabeth Dole Home Care Act*. They projected that the bill would cost \$16.1 billion in discretionary spending and \$8.5 billion in mandatory spending, totaling \$24.6 billion over ten years. CBO estimated that the section raising the non-institutional expenditure cap would cost \$24.5 billion over this time frame. Due to this provision contributing to the vast majority of the cost, it has become the subject of debate and has been consequently removed from the Senate version of the bill.

### **Addressing the Cost:**

The non-institutional care expenditure cap is VA’s ability to pay providers of in-home health care services up to 65% of the total cost to the VA if it had provided care within a VA facility (38 U.S.C. § 1720C(d) (1997)). When veterans—those of whom usually have complex care needs—reach this limit, their families and caregivers are required to bear the other 35% of the costs or must place their veteran in institutional care.

Not only is in-home care essential to our community’s well-being, but we are concerned that the CBO score does not properly reflect the true costs of implementing this provision, especially when considering more complex care facilities. It is the opinion of our experts, as well as a coalition of military and veteran-serving organizations, that the projected cost estimate is unintentionally inflated. At the high end, approximately 500 veterans have reached the 65% cap and not all of them need it increased to 100%. Because the share of veterans reaching the cap is so low, it is improbable that adding funding for this small group will cost \$24.5 billion over ten years. We strongly encourage the respective House and Senate Committees on Veterans Affairs to challenge the CBO score and ensure that this was calculated properly.

In addition to reevaluating the cost, it is important to acknowledge the money that is saved on a continued basis by veteran caregivers across the country. In order to put the value of family caregiving into perspective, CBO should also calculate how much it would cost if every veteran who qualified for institutional care at the VA elected to utilize it. We are confident that cost over ten years would be far greater than the projected cost of raising the non-institutional expenditure cap, especially as [AARP recently reported](#) that civilian family caregivers nationwide contribute over \$600 billion in unpaid labor each year.

## **The Non-Institutional Expenditure Cap's Impact:**

In addressing this issue, it is crucial to go beyond the numbers and consider how it operates in practice. For caregivers, raising the non-institutional expenditure cap would be a much-needed relief for their families. Caregivers like Karee, Jim, Mary, and Lara know this struggle all too well.

In North Carolina, Karee and Jim are impacted every day by this cap. Karee and Jim are both Army veterans and they have nine children, many of whom have followed in their parents' footsteps and become Army officers too. One of those children was Kimmy, who at 25-years-old following a deployment to Afghanistan, suffered a Traumatic Brain Injury (TBI) while stationed in Italy. Karee and Jim now care for a 34-year-old Kimmy. Kimmy requires 24-hour care as well as tube feeding, frequent pulmonary care, support with all activities of daily living (ADLs,) and additional therapies.

Despite living just outside of Raleigh, a city home to exceptional healthcare facilities and North Carolina's state capital, no facility would accept Kimmy within 40 minutes of her parents' house. Kimmy receives her care at home and is enrolled in Veteran-Directed Care (VDC), which pays for a small portion of her healthcare costs. Kimmy's pension from the Army funds the rest, including income for professional caregivers to assist with her 24/7 care. Together this costs upwards of \$200,000 annually and leaves little for additional expenses.

Theoretically, Kimmy could receive care in an institution for the rest of her life. Despite the potential benefits, her parents are willing to take on these responsibilities in order to ensure that their daughter has the best quality of life possible. If placed in institutional care, Kimmy would suffer immeasurably and miss the interactions with her eight brothers and sisters, going to family events, and her vast community of friends who regularly have her over in their homes. Karee and Jim would be unable to see Kimmy regularly and would be an hour away should anything happen. Despite all of the current challenges that come with caring for Kimmy at home, Karee and Jim do it anyway because it is the best option for their daughter.

Two hours south of Raleigh, another family is experiencing similar struggles. Mary cares for her husband, Tom, who is 68 years old. He served in the Marine Corps from 1972 to 1975. In 2010, he was diagnosed with service-connected Amyotrophic Lateral Sclerosis (ALS). He has been living with ALS for nearly thirteen years. Mary is 63 years old and retired several years ago to become his full-time caregiver. He has specifically requested that he remain in the home through the end of his life, rather than be cared for in a facility. Mary is fully supportive of this decision and can see no other way for him to live out his days than at home surrounded by family, pets, music, and his paintings. Mary currently does not have outside help to care for Tom, but likely will require it in the near future. Because of the expenditure cap, she will care for Tom at home without the appropriate amount of care and it will come at a great expense, both financially and physically. When asked what keeps her up at night, she replied, "that the disease will consume me from exhaustion, and I will die before him."

This experience is not isolated to the East Coast. In Texas, caregivers are facing similar challenges caused by the non-institutional expenditure cap. Lara was the wife and caregiver to her husband Tom, a US Air Force veteran. Tom was diagnosed with service-connected ALS in 2016, received a tracheostomy and became ventilator dependent in 2019, and passed away from the disease on July 15, 2022.

For the last three years of his life, he was paralyzed, received nutrition and medication through a feeding tube, required a tracheostomy and ventilator to breathe, and communicated using eye gaze technology. Tom's care was considered high acuity, meaning not only did he need help with all aspects of Activities

of Daily Living, but he also required the support of his ventilator and circuits, feeding tube, and constant evaluation for skin breakdown. His care was like the care received in a hospital-level ICU. Lara was able to keep Tom in their home, where he wanted to be in the last years of his life, surrounded by family, friends, and his loyal service dog, Lou. Lara was not a trained medical professional, but she cared for Tom to the best of her ability, despite her fear and uncertainty.

Tom's care was 24 hours, seven days a week. Tom's ventilator had to be monitored at all times and provide the required suctioning, as well as ensure that he was regularly adjusted to avoid skin deterioration. Tom required the use of a Hoyer lift to be moved out of the bed for toileting, showering, or to be placed in his wheelchair. It took Lara over a year of advocating to the Central Texas VA to have skilled nursing approved to provide much-needed skilled help in the home. Her VA found a path forward to getting the care she needed in the home, but her experience is very much an exception and not the rule.

Solitary caregiving, like what Lara provided to Tom prior to receiving skilled care, led to extreme physical and mental exhaustion. The cumulative exhaustion felt by Lara was not only unhealthy for her as the caregiver, but also for the care recipient—the husband she adored. On several occasions, Lara's exhaustion did lead to her making errors in Tom's care; from minor ones like forgetting to restart the feeding pump after toileting to more serious ones of inadvertently turning the ventilator off. The lack of in-home nursing support, sleep deprivation, and grief took a toll on Lara's mental and physical health, and Lara began experiencing suicidal ideations.

For high acuity veterans and their caregivers, having skilled care in the home is so much more than just a break in care responsibilities or respite for the caregiver. It is essential for the health of the caregiver. In Lara's case, having skilled care in the home enabled her to get more than 2-3 hours of sleep most nights. Skilled care also allowed for moments that would allow her to give her attention to their teenage son, Trey, and gave her space to step away to allow herself to grieve her husband and the life they shared before ALS entered it.

Keeping the 65% cap on care services the VA offers, especially for high-acuity veterans, is detrimental to the caregiver's physical and mental well-being, which ultimately reduces the quality of care for the veteran. Caring for high-acuity veterans in the home is possible with services offered by the Veterans Health Administration, especially when the veteran is adamant about living their life in their home. Providing a path forward for these high-acuity veterans and their families and removing the 65% cap is vital for the well-being of military families.

The unfortunate reality is that there are so many other families who are just like Karee, Jim, Mary, and Lara. They are parents who will never stop caring for their children and spouses who are taking on more than they ever expected. Not only are veterans lucky to have them by their side, but our nation should feel lucky too.

## **Conclusion:**

Senator Elizabeth Dole was honored to lend her name to legislation that is uniquely focused on improving caregiver resources and supporting care within the home. Congress has an opportunity to invest in this population and an obligation to ensure that veterans receive the treatment that they want and deserve. It is critical to include provisions that address the non-institutional expenditure gap and continue to provide solutions for those wanting to receive care at home.

Passing this legislation helps veterans and their caregivers get the services they need now while also building the infrastructure needed to serve veterans into the future. Caregivers cannot afford to wait any longer. Thank you for considering this critical issue, and we look forward to the *Elizabeth Dole Home Care Act* becoming law.