Testimony of Mrs. Mary Ward
On Behalf of
The Elizabeth Dole Foundation
Senate Committee on Veterans Affairs
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Strengthening Services for Veterans with Spinal Cord Injuries, Diseases, and Disorders

Chairman Moran, Ranking Member Blumenthal, Members of the Committee, thank you for inviting me to testify today.

My name is Mary Ward, and I am the wife and full-time caregiver for my husband Tom, a Marine Corps veteran diagnosed with service-connected ALS over 15 years ago. Tom was 55 years old, and I was 50. We have two children and three grandchildren and live in Wilmington, NC. I am a retired teacher and a 2016 Elizabeth Dole Foundation Fellow.

I would like you to pause and think of a simple pleasure you enjoy by yourself. It could be that first quiet cup of coffee in the morning. Perhaps it's a solo drive with your favorite playlist. For me, it has long been a Starbucks Vanilla Bean Frappuccino — three pumps of vanilla, fat-free milk, and whipped cream.

For years, I thought the joy was in the ritual: stopping after grocery shopping, sitting in my car, sipping it while listening to music. But this past July, I realized I had redefined what joy means to me and the various ways in which it manifests itself in my life. Now, the joy that comes when I can drink that Frappuccino is knowing there is a nurse at home with my husband, ensuring he is safe and supported. In that moment, I am not a caregiver. I am me, doing something normal. That is the gift of respite. And it took eight years to get there.

My Caregiving Journey

To understand the vital importance of long-term care supports available through the Department of Veterans Affairs, it helps to know our journey.

I have been Tom's caregiver for decades. In 1993, he contracted encephalitis that left him with cognitive impairments, preventing him from ever working again and in 2010, he was diagnosed with Amyotrophic Lateral Sclerosis (ALS), for which he is service-connected. Veterans are more than twice as likely to get ALS as non-veterans.

In September 2013, he was also diagnosed with type 2 diabetes. Tom is rated 100% permanently and totally disabled, and ALS and diabetes are competing forces. ALS is considered a hypermetabolic disease, which complicates managing blood glucose, and as a result of the ALS, Tom is unable to give himself insulin injections.

The daily care for Tom ranges from assistance with activities of daily living (ADLs) to medication management to making his meals, doing his laundry, keeping the house clean, driving him to places he wants to go or needs to go, etc. Independent living is not possible for him. A typical day looks like this:

- Help him when he wakes to get from bed to wheelchair.

- Check his fasting blood glucose.

- Get him dressed.

- Give him his medications.

- Check his blood pressure.

- Give him coffee and a small bite to eat.

- Check his blood glucose. I do this throughout the day.

- Put his leg compression device on for an hour.

- Do a cough assist (assistance provided to ALS patients who no longer have the respiratory strength to clear phlegm from the lungs) before we shower.

- Shower, dry, groom, and dress him for the day.

- Do whatever needs to get done in the morning in terms of food shopping, laundry, etc. If I'm going out of the house, I will take him with me.

- I make all of his meals, cutting up food that needs it, pushing food onto his fork, and always determining blood glucose levels before we eat. Whatever his level is, then I figure out based on what we are eating how much insulin to give him. There is never a meal that we do not do this function. It has become a part of eating.

- Some nights, the alarms on his glucose monitor wake us. They go off once, twice, sometimes three times. The alarms indicate his glucose levels are dropping too low or rising too high. Either way, it requires attention.

- At 1 p.m., we have a private duty nurse to care for him until 5 p.m. Having a nurse is new for us. Approval for this level of care finally came in July 2025.

- During the day and evening, there are many small tasks I do and assistance I give to Tom. It isn't easy to enumerate them all. The bottom line is he cannot live independently. This understanding must be the takeaway from this "day in a life."

Tom's ALS diagnosis came in June 2010, a few days after our 30th wedding anniversary. I was teaching high school, and we were living in Durham, NC. The chief neurologist at the Duke ALS Clinic was the diagnosing physician. He was also a neurologist at the Durham Veterans Affairs Medical Center (VAMC). Through his social worker and the Paralyzed Veterans of America, he became service-connected with a rating of thirty percent. At that time, that was the initial rating for veterans with ALS, but thanks to the tireless advocacy of several veteran service organizations, the presumptive rating was changed from thirty percent to one hundred percent, permanent and total (P&T), in 2012.

Struggles and Small Victories

Unfortunately, the two years between Tom’s diagnosis and this vitally important policy change were difficult, as obtaining the support we needed from the VA was anything but easy. The VA, for example, denied Tom the Specially Adaptive Housing (SAH) Grant and adaptive vehicle grant because, even though he had been diagnosed with a chronic, progressive disease, he was not yet rated 100% P&T. Although the VA did give him a power wheelchair, it stayed in the garage because we didn't have a handicap accessible home at that time. Finally, after the wheelchair was delivered, the VA approved the vehicle grant. Fortunately for Tom, he has a slowly progressive version of ALS, which meant we could withstand these delays.

Knowing the destructive nature of ALS, we got busy developing a plan for living with it that would work for both of us. In 2012, I gave notice at my brick-and-mortar school, and we moved to Wilmington, NC to downsize and save costs for what we know will be my future as a widow. I accepted a virtual teaching position for Advanced Placement Government and Politics with the state of North Carolina. When I did that, I left my state retirement behind; this job came with no retirement benefits.

Finally, in 2013, the VA approved Tom for the SAH grant, but that didn’t mean our wait was over. From start to finish, having the house adapted and made accessible took 27 months. By the time the VA had approved all of the specifications for the project, it was January 2015, and the contractor didn’t finish the work until July of that year. It is not a process I would want to repeat.

In 2016, due to our move, we moved Tom's VA primary care to the Wilmington Community-Based Outpatient Clinic (CBOC). The CBOC in Wilmington opened for care in 2013 and is part of the Fayetteville VAMC. We had heard good things about it, and we knew that it would save us from the long two-hour and forty-five-minute travel to the Durham VAMC. What we didn't understand, though, was that when we did that, we lost direct access to the specialty care that the Durham VAMC provides for veterans with spinal cord injuries and diseases. We would have to get referrals for each service from Fayetteville to go to Durham, and when the Durham VA ALS physician ordered equipment and/or services, it would have to go through the Wilmington CBOC Patient Aligned Care Team (PACT). Perhaps that sounds easy enough to do; however, all it did was add confusion and delays.

One reason we moved Tom’s care to the Wilmington CBOC was to access the VA’s Home-Based Primary Care program (HBPC). HBPC is a vital and supportive program that many veterans benefit from because it minimizes travel requirements for those with mobility challenges. However, because we do not live in the catchment area for Durham's HBPC services, we could only access HBPC through the Wilmington CBOC. Therefore, we had to choose. We could either access HBPC through Wilmington or have direct access to his ALS care, but we could not have both. After a series of mishaps due to this situation, including the inability to address a malfunction with Tom’s non-invasive ventilator—without which he becomes hypoxic—we made the choice to give up HBPC and move all care to Durham. As much as we sorely needed it, it wasn't worth all the unforeseen and dangerous complications we experienced trying to navigate the bureaucracy.

Did Tom's care suffer during this time? No, I don't think so but only because I wouldn't let that happen. I leaned heavily on our non-VA primary care physician during that transition and continue to do so. Did the quality of my life suffer during that time? Absolutely. I carried the burden for him then and continue to do so today.

This lack of flexibility in the system forces us to choose between necessary services that could improve Tom's quality of life and even potentially extend his life expectancy. ALS and other diagnoses that fall under the spinal cord injury service are often very complex and don't fall into rigid categories—allowing some level of flexibility in care and services as well as comprehensive care coordination would maximize the strengths of the VA and emphasize the concept of veteran-centric care. For example, an ALS clinic of excellence, such as the Duke ALS Center, provides soup-to-nuts care on a clinic day. The patient is assigned a clinic room when they arrive, and all of the specialties come to that room throughout the day: pulmonology, respiratory therapy, physical therapy, occupational therapy, speech therapy, social work, nutritional support, and neurology. It's a long, exhausting, but thorough and efficient day. We use Medicare benefits for this because the VA will not provide a community care consult for the clinic as a whole, as each specialty has to have its own referral.

These experiences have taught me something many veterans and their caregivers know all too well: the VA system has incredibly beneficial programs and services, but navigating that system is often confusing, fragmented, exhausting, and sometimes downright dangerous.

Over the years, I have had to escalate issues — from obtaining the non-invasive ventilator support mentioned above to hospital beds — up the VA chain of command, sometimes as far as the VISN director. Sometimes this advocacy has worked, but the one battle I kept losing was access to respite care. In 2017, the VA denied respite care while I was attending the Elizabeth Dole Foundation Convening in Washington, D.C. I pieced arrangements for Tom's care together to make it work, but it was far from ideal.

After learning about Veteran-Directed Care (VDC) from another Elizabeth Dole Foundation Fellow in North Carolina, I decided to apply for it for Tom. For those who are not aware, VDC is an innovative program within the VA that works in partnership with the Department of Health and Human Services. It offers the veteran a budget for personal care services and other expenditures to spend in a "consumer-directed" manner. In other words, the veteran has the flexibility to hire and fire support for Home and Community-Based Services, offering more flexibility and control of care to the veteran and caregiver. For those who can access the program, it is very popular and, importantly, often represents a cost savings for the VA.

However, even though I knew another veteran who was enrolled in VDC through the Durham VA, I was told by a Durham VA social worker that VDC simply didn't exist there. She was adamant about it. I let it go. I didn't have the energy to take on another battle while caring for Tom and dealing with his increasing health complications. I know many caregivers across the country who have faced similar challenges in accessing this program. They are given incorrect information, and they are unsure how and where to pursue it. It's frustrating beyond measure to know that these programs exist and not be able to access them.

Fortunately, in 2020, with the pandemic and Tom's diabetes becoming increasingly insulin-resistant, I began to see improvement in VA responsiveness. Our respiratory team became more helpful, prosthetics filled orders more quickly, and our Caregiver Coordinator from the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC) Caregiver Coordinator became an anchor of support. She has walked alongside us ever since, providing not just resources but also compassion and understanding.

Still, my attempts to access VDC were often foiled, until last year, when we finally got approved and were enrolled. Unfortunately, this still did not mean we received any services. When I asked for a timeline regarding funding and the actual provision of services, the response was: "30 days, 60 days, 90 days — I just don't know." With that lack of certainty and seemingly zero sense of urgency, we reluctantly withdrew from the program.

In the meantime, I leaned on my adult daughter and a friend, Lara, another Dole Caregiver Fellow and a survivor. Her veteran died from ALS over three years ago. Last year, it was Lara who traveled to care for Tom so I could be present for my daughter when she delivered her baby, my precious grandson Hayes. I didn't even consider asking the VA for help; I knew what the answer was likely to be.

The Turning Point

In the spring of this year, I realized I couldn't do it alone anymore. Tom agreed. His ALS progression was more pronounced, his diabetes care grew more complex, his glucose was dangerously erratic, and I didn't realize how exhausted I was from the last few years of 24/7 caregiving. In June, things came to a head when Tom became very sick from a diabetes medication he was on, which Tom's doctor then took him off. But since it was the only medication holding his insulin resistance at bay, his doctor cautioned that I would need to be even more vigilant. I seriously wondered, how? How could I be any more vigilant than I was? It wasn't humanly possible to continue as we were, to continue alone like I had been doing.

Through the resources of the Elizabeth Dole Foundation, together we pursued VDC and, at their encouragement, skilled nursing care as a possible alternative. At first, I doubted Tom would qualify for the skilled care of a nurse. He wasn't trach'ed and vent-dependent, which seemed to be the criteria. But through a deep and vulnerable conversation with EDF staff, I realized that skilled nursing care was the safest route for Tom and the way forward for me to have true respite. The hard-working staff at the Elizabeth Dole Foundation took our fight to the highest levels at the VA, and the VA actually approved private duty nursing care. It may not seem like a big thing to some people, but having someone else advocate for us was a huge relief. When we were approved, it was quite a moment for me. Maxim Healthcare, the agency we use for skilled nursing care purchased through VA, has made the process seamless and has allowed me, for a few hours a week, to be me again and not a caregiver. A long time ago someone asked Tom about me as his caregiver. He said she is my wife first and caregiver second. That has insidiously changed over the last few years. The benefit for me is clear, and the care I provide Tom because of respite is exponentially better. My sense of humor has returned. At the end of the nurse's shift, I look forward to seeing him.

Now, five days a week, from 1–5 p.m., a nurse comes into our home. The nurse monitors his health, catches issues I might miss, and allows me to step outside of my caregiving role for a few precious hours. Just last week, one of our nurses discovered Tom's blood pressure was running high, despite medication. This finding likely prevented a crisis.

For me, those hours are life-giving. I spend time with our youngest grandson, run errands, or simply sit in peace. I drink that Frappuccino, and for a moment, I remember who I am outside of caregiving.

What This Means for Policy

I share our story because while we have finally found the proper support, it should not have taken eight years, relentless advocacy, and national-level intervention to get here.
Too many caregivers give up before they reach this point. They go unseen, unsupported, burned out, and sometimes feel the only way out is to harm themselves. Simply put: veterans suffer when their caregivers suffer.

I therefore urge this committee to act on the following:

- **Expand and strengthen access to respite and home care** for veterans with complex conditions like ALS and spinal cord injuries, regardless of where they live. Those in rural areas need access to support, but even those living in places like ours with available resources are often not able to access needed support because of overly burdensome bureaucratic requirements, as well as staff shortages. *The Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* was signed into law on January 2, 2025. However, implementation of numerous sections that would help create a more straightforward path forward for respite, skilled home care, and expanded access to mental health care for caregivers has yet to occur nationally.

Relatedly, the Elizabeth Dole Foundation also supports the expansion of the innovative Technology Enabled Respite Homecare Model for which a successful preliminary pilot program concluded last year. The pilot offered access to high quality in-home care for veterans who need long term services while, at the same time, offering more control to the veteran and caregiver and increasing compensation for providers. The Elizabeth Dole Foundation encourages Congress to work with VA to further explore this model of care as an option for respite for veterans and caregivers.

- **Demand the immediate implementation of Section 120 of the Dole Act** so that there are no excuses preventing the provision of appropriate care in the home for the individual. This provision removed the 65% cap on non-institutional care expenditures, allowing the most vulnerable veterans to stay in their homes with appropriate care and support. While we have not run into this cap yet, too many other ALS, Multiple Sclerosis (MS), brain-injured, and spinal cord families are facing a horrible choice—stay in the home without appropriate support for the veteran or caregiver or move to a skilled nursing facility that will potentially shorten life expectancy and lower their quality of life standard.

- **Promote better proactive and holistic care coordination** so veteran families, especially those with the most complex needs, are not left to navigate the VA on their own. To help achieve this goal, the Elizabeth Dole Foundation supports the *Coordinating Care for Senior Veterans and Wounded Warriors Act,* which would establish a pilot program for certain veterans enrolled in both Medicare and VA to better manage and coordinate care. In addition, the Elizabeth Dole Foundation encourages Congress to work with the VA and stakeholder organizations to identify positive steps forward, such as the VA's establishment of the Lead Coordinator process intended to offer one point of contact for some complex cases, as well as address ongoing challenges, including those outlined here, that prevent veterans from accessing care and services promptly. The veteran community does not always need new programs. In many cases, we simply require access to the existing programs and services designed to help us.

- **Demand the expeditious discussion of and implementation of section 129 of the Dole Act.** "The Pathway to Advocacy," as it is called, requires the Secretary to establish a process to recognize outside organizations to assist veterans, caregivers, and survivors navigate the programs and services of the Veterans Health Administration (VHA). Similar in concept to the advocacy available from veteran service organizations in filing claims through the Veterans Benefits Administration (VBA), the establishment of this process would be a lifeline for families like mine struggling to navigate a very complex system and would complement the Department's existing social work and case management programs. We were fortunate to find people willing and able to help us, but, currently, not every veteran can easily get that level of support.

- **Ensure consistency in Veteran-Directed Care implementation and funding** so families do not face months of uncertainty while paying out of pocket. The Dole Act codified this program to push the VA in this direction—ensure its swift enactment with the appropriate staffing across VDC and all of Geriatric and Extended Care (GEC) to make sure no other family endures our same struggles.

Closing

For those with devastating injuries and illnesses, long-term care support, especially respite, is not a luxury. It is not optional. It is essential—for caregivers, for families, and for the veterans who depend on us.

I am grateful for the nurses who now come into our home, for the Elizabeth Dole Foundation's relentless advocacy, and for the VA staff who have stood by us. But the care we now receive should not be the exception reached only after years of struggle. It should be the standard.

For every Frappuccino moment I now enjoy, there are thousands of caregivers still waiting for that moment to take a breath. Please make it possible for them to find joy again, and to see and feel that they matter, too. Their veterans' care, and sometimes their lives, depend on it.

Thank you.