

Mary Ward
Caregivers' Testimony before the
U.S. Senate Special Committee on Aging
6/14/17

Good afternoon and thank you Chairman Collins and Ranking Member Casey for inviting me and my husband, Tom, to this hearing on military and veteran caregivers. I am humbled to be here alongside a force of nature like Senator Dole, an advocate like Ryan Phillippe, an expert like Terri Tanielian, and my peers.

I became a Dole Caregiver Fellow in 2016, but my journey as a caregiver started long before then. In June 21, 2010, Tom was diagnosed with ALS. Prior to that, in 1993, Tom had been disabled from encephalitis. He has required care from me since then, but the all-encompassing care of ALS is intense.

I had his care figured out and organized until ALS came along. It's a devastating diagnosis. For me it was like getting sucker punched. Tom and I are that couple that fell in love almost instantly in 1979. My grief has known no bounds. I know how this disease works. It will steal his life, and if I am not careful it will take mine as well. The work ahead as his caregiver is daunting at best. I am certain that I am not up to the task, alone, yet for the most part I know I will have to be.

In 2008, ALS was made a presumptive illness for veterans. Veterans are twice as likely to get ALS as non-veterans and more than 4,500 veterans at a given time have ALS. Tom served in the US Marine Corps from 1972-1975 so he qualified for benefits. Enter the VA into our lives.

I had not considered myself Tom's caregiver until later in my life. I was committed to our vows and love for each other. A caregiver to me meant someone who was paid to come in and provide services. In 2013 I saw an interview with Senator Elizabeth Dole about caregivers; that was my epiphany, that I was a caregiver.

ALS is a catastrophic disease: physically, emotionally, and financially. There is never a day that goes by that I am not grateful for all the VA does to support Tom as he battles ALS. The challenge lies in ensuring that he gets what he needs in a timely fashion: the correct breathing mask,

medications, equipment, and so on. While I work on managing resources available from the VA, at the same time I am taking care of Tom and teaching Advanced Placement US Government and Politics online. Tom's need for assistance is non-stop. He is moving towards dependence rather than independence. That is never going to change.

One huge worry I have is the financial aspect of my future. I teach high school online so I can care for Tom but have done so at a significant salary reduction which has impacted my future retirement funds. I save diligently but I am deeply concerned that as his dependence grows I will need to pay for assistance out of pocket as the VA will only provide 28 hours of care a week, and that will never be enough if Tom lives to full paralysis.

We have two adult children who cannot assist in their dad's care. Our daughter is a 2nd grade teacher in Charlotte. Our son is a sergeant first class with 14 years in the Army and currently a drill sergeant. Their dad is their hero and would help in a heartbeat if it was possible. The best thing they can do is to continue to grow their careers; that is the kind of help we want from them.

Being a Foundation Fellow has been life changing for me. I have developed lifelong friendships with other fellows. Senator Elizabeth Dole has encouraged us to be "solutionists" and so we are, with each other, and with other caregivers.

As a pre-9/11 caregiver the VA offers me almost nothing. I receive no caregiver training from the VA, no stipend, no support other than a monthly national call with focused topics, and a few months ago was denied respite hours.

I am one voice, among many, who need consistent, and compassionate help as we carry this heavy responsibility caring for our veteran. And there is still so much that we don't know. We need to cultivate a better understanding of the needs of caregivers through research like the kind you heard about from Terri. And we need action. I hope you will consider passing the Military and Veteran Caregiver Services Improvement Act to help caregivers like me. Thank you for your time and consideration today. I welcome your questions for myself and my husband, Tom.