

*Statement of Vanessa Chism, 2024 Elizabeth Dole Foundation Caregiver Fellow before the House
Veterans Affairs Committee*

September 25, 2024

Chairman Bost, Ranking Member Takano and Members of the Committee, thank you for providing me the opportunity to speak today. I am honored to testify alongside, Steve Schwab, Elizabeth Dole Foundation CEO, representing veteran caregivers. I am sharing my story today, but I would like you all to keep in mind, that I am not an anomaly. There are thousands of other caregivers like me who are experiencing these struggles, yet they bravely tend to our nation's heroes every single day. This nation will never be able to repay them for their sacrifices.

My name is Vanessa Chism, I am the wife and caregiver for my husband, Cody. I vividly remember being in middle school and a young man in his big puffy starter jacket catching my eye in the carpool pick up line, we became friends at just 12 years old. Just a few short years later he won my heart as we quickly became high school sweethearts, marrying soon after graduation in 2002. We had so many plans together. In 2003, he decided to join the United States Army as a combat medic. I fully supported this life altering journey we both were about to embark upon, and I was so excited for our future. While at our third duty station in Mannheim Germany, he deployed in support of Operation Iraqi Freedom, and in December 2008, he came home. The relief that your soldier was coming home is immeasurable, however I naively thought he was unscathed from the atrocities of war simply because he was coming home without being medevac'd out of the combat zone. The moment I saw him in the high school gymnasium, I knew I was wrong. I kept hearing that reintegration took time, but I knew something was not right.

Ultimately, my husband was medically retired from Walter Reed Army Medical Center in 2011 after spending almost two years in the Warrior Transition Unit there with a diagnosis of PTSD with Bipolar Disorder and an assortment of other diagnosed injuries. However, this seemed to be the classic diagnosis of many soldiers medically retired during this time and did not fully explain my husband's neurological symptoms. He couldn't even remember that our baby needed to wear diapers or significant events that occurred a day prior.

After retirement things continued to spiral medically for my husband. There was a continued neurological decline and a sudden onset of seizures. A private medical facility was able to appropriately diagnose him in 2012. It was determined that my husband had multiple traumatic

experiences, exposures to toxic substances, and blast exposures in combat which likely caused PTSD, Moderate Traumatic Brain Injuries, Seizures – Epileptic and Non-Epileptic. While suspected for many years, it wasn't until 2024 that he was diagnosed with Chronic Traumatic Encephalopathy (CTE) by the VA. "Clinical symptoms of CTE include progressive affective lability, irritability, distractibility, executive dysfunction, memory disturbances, suicidal ideation, and in advanced cases, cognitive deficits and dementia." (1)

I have spent the last 15 years of my life as his caregiver, dedicated to tending to him, struggling, advocating for and ensuring that no matter what my husband received the best medical care possible. It has taken me 15 years, collegiate education in Psychology & Behavioral Neuroscience, 6 Veteran Healthcare Facilities, multiple private physicians spanning across 4 states & the District of Columbia to even begin to understand his actual diagnosis and the care and services available to him and our entire family. He requires supervision at all times, and I manage every aspect of his life. Our lives are full of medical appointments, countless hospital stays and the never-ending medication management. His daily life is afflicted with chronic suicidal ideations, migraines, frequent seizures, episodes of psychosis, chronic pain, and cognitive impairment leaving him unable to care for himself independently. While he is still here physically, I have lost who my husband once was. We endure the everchanging neurological decline resulting from traumatic brain injuries, and it has forever changed our lives. Every single day my three children and I watch him slowly decline as his brain continues to fail him. We have had to face decisions that no one should ever have to make. But because of those decisions we have learned to fight, we have learned to advocate, and we have learned to prevail as a family.

There are programs within the Department of Veteran Affairs established to provide assistance for families like mine. However, accessing them is extremely difficult, even with my years of experience. I have been enrolled in the Program of Comprehensive Assistance for Family Caregivers (PCAFC) since 2012, currently considered a legacy participant, which means my husband & I were enrolled in this program prior to October 1, 2020. On November 5, 2021 after going through the new evaluations with the new eligibility criteria, and despite VA assessors stating multiple times that my husband is not capable of caring for himself and he is unable to self-sustain in the community I received notification that my husband was being discharged from the PCAFC program based on the reasoning that he would not need continuous care for more than six months. They wrote specifically, "veteran has continuous Suicidal Ideations, Veterans depression impacts motivation to eat/drink/perform hygiene, veteran's chronic MH conditions impact his memory/judgement/reasoning/problem solving/other aspects of

executive functioning, veteran is unable to manage medication in a manner to maintain his health and well-being or safety.” I am well aware that I am fortunate to have VA Caregiver Coordinators who have always provided me with all of the support within their capacity, but, unfortunately, their authority is very limited. Even they were shocked that we received notice of discharge from the program and were not even sure what the future would hold for my husband. Thankfully Quality of Life Foundation, an Elizabeth Dole Foundation grantee, specializes in VA PCAFC program appeals and they were able to provide me with much need guidance on how to navigate and appeal the PCAFC discharge.

It was ironic that just a few months prior to receiving this decision, I became very ill after contracting the Covid virus. Like many of us, I had to isolate in order to protect my family, especially Cody from contracting the virus from me. I did so as much as possible, but during this time Cody started to become ill and was profusely vomiting. This is not completely abnormal for him as he has a chronic gastrointestinal issue. However, typically I am around to assess the situation and ensure proper treatment. He was able to hide the extent of the severity of what was happening to him due to my illness and me not having direct supervision of him. After a few days, I realized how bad he was and immediately put a mask on, drove him to the local emergency room and asked them to please help him. My husband did not have the cognition to realize that he was so ill his body was experiencing sepsis from a lodged kidney stone. This required him to have multiple surgeries and hospitalization. Yet the new VA PCAFC assessment team deemed he didn't need a caregiver. I am currently among the approximately 14,000 other legacy participants in the pause, awaiting the VA to disclose our fate, which leaves us all so vulnerable and unsure of what the future holds for our Veterans.

Additionally, enrollment in the PCAFC program entitles me to a minimum of 30 days of annual respite care provided by the VA. I have been enrolled in the PCAFC program for 12 years and I have never been able to access any respite care through the VA. While living in Tallahassee, Fl. in approximately 2018 and Naples, Fl. in approximately 2022, I requested respite care multiple times, and I was approved but there were no available providers. In 2024, having moved north to get better care at the Martinsburg, West Virginia VA medical facility, I again requested respite through my Caregiver Coordinator but once again I was told they were unable to locate a provider. Just recently I switched my husband's primary care to the Baltimore, VA and have been approved and told providers were available. However, I need to provide requests at least two weeks in advance in order to receive respite, which again creates a barrier to receiving the service when I need it. I was successful in receiving respite care once, it was through the Elizabeth Dole Foundation approximately 3 years ago. At that time, I was spending every Friday

driving my husband to the VA clinic which was over an hour away to pick up medication because the VA could not dispense more than 7 days of this medication at a time. The respite provider drove and assisted my husband with obtaining this medication and then took him with his service dog, Champion to a dog park to play. These few hours gave me the opportunity to volunteer at our youngest daughter's school, knowing that my husband was safe. The simple ability to not have to worry for just a few hours is invaluable.

Currently my respite is provided by my 3 incredible children who are the ages of 23, 17 & 10, they too have dedicated their lives to being secondary caregivers to their father. Only my oldest son "knew who his dad was before war." They are truly incredible Hidden Helpers. I admire their resilience and strength every single day. Without apprehension they step in to be their dad's caretaker, whether that be driving him to the store & making sure he remembers why he's there, knowing what to do when he has a seizure, understanding when plans have to be cancelled, or monitoring their dad doing simple daily tasks. They are always there to help me.

The sacrifices they have had to make has impacted their lives. Both of my older children have had periods of time in their lives where they needed professional therapeutic services to help them navigate their feelings and experiences with their father. Thankfully non-profit organizations like Wounded Warrior Project helped me ensure all barriers were removed so that they could receive therapy. And Elizabeth Dole Foundation holds their annual Hidden Helpers Summit, bringing together children caregivers for informative, bonding experiences.

While I recognize the challenges, this life presents for them, I like to focus on the positive impacts being Hidden Helpers has had on my children. All three are incredibly kind, compassionate, flexible and always dependable. These are characteristics they not only present within our home but throughout our community as well. They have made sacrifices and their lives have been both positively & negatively impacted but in return they have their dad at home with them. It may not be the dad in a sense that everyone else may have, but he's their dad and that can never be replaced.

I am also aware of the Veteran Direct Care (VDC) program through the VA as well. However, this program is currently not offered at all VA facilities. While it was offered at some facilities where my husband has been enrolled, I have found that staff at VA Healthcare Facilities are not fully trained regarding the VDC program and is often only available in limited catchment areas. I

have had to inform social workers at multiple VA facilities of the VDC program and explain to them the process they need to follow in order to determine whether my husband would qualify. This program could allow me to directly hire trusted individuals, who are familiar with my family, my husband's needs and provide me with respite care. Yet I have not been successful thus far in accessing this program. This program could be an asset to me and the thousands of other caregivers who need and deserve a break so we can be at our best when caring for our veteran. We aren't asking for breaks for extravagant events --something as simple as going to the grocery store, volunteering at our child's school, everyday tasks that most people can do without much thought.

Another program I have found to be beneficial yet challenging to access is the Community Care Network. When VA providers have found that it is appropriate and necessary, they have referred my husband out to community medical providers to access medical care. My husband received an updated MRI of his brain through community care in a much timelier manner than the VA could provide. However, while the medical records were sent to the VA healthcare facility, VA providers can still not access those records. So, I ensure that I keep accurate medical documentation to provide each provider when needed. Additionally, when referred to a community care podiatrist my husband found multiple hurdles attempting to access care. The podiatrist provided exceptional care yet was not permitted by the VA to provide necessary medical equipment. After waiting months for the VA to send a walking boot, which the community care podiatrist prescribed, to determine what was impeding mobility for my husband, it took me driving over 3 hours round trip and waiting for over an hour to discuss with the community care liaison how to fix this problem. The delay was the result of the community care provider being given the wrong VA form to complete requesting the walking boot. I took the correct form to the provider, submitted it and the medical equipment was delivered by the VA. The Community Care Network can be an incredibly beneficial program for veterans ensuring they receive appropriate medical care in a timely manner. This program if made fully accessible can help alleviate burdens placed on our veterans and therefore caregivers, who need access to timely, high quality medical care.

I could never imagine a decision my husband made when we were 20 years old would alter the course of our entire lives. I became my husband's full-time caregiver at 26 years old. My hopes, my dreams, my forever changed by my husband's decision to support our beloved country. Yet I would not change where I am in life, as I truly believe every single thing happens for a reason, a reason I may not understand, but I know that God's plan is far better than mine. Being my husband's caregiver is a choice I make and 15 years into this, I am fully aware of the sacrifices I

have made and will continue to make. I spend so many hours providing my husband with case management services and always assuring he is cared for every hour of every day. My life may look vastly different than others and that is okay because it is my choice.

As I tell my children, we get to decide the perspective that we choose to view our circumstances. We choose to make the most of each day. Sure, some days my husband can't get out of bed but some days he can, some days the seizures are hard and plentiful but some days there are none; we choose to laugh at how many times we have to tell him the same thing over and over because one thing is certain, he is going to forget. As I mentioned earlier in my statement, we made yet another move to Maryland from South Florida, a few years ago seeking better medical care for my husband, and we also started a small homestead at that time. It has always been a dream of ours to live sustainably, in a peaceful country setting with entirely too many animals. Our family, especially my husband, finds joy in raising his animals, and we as a family make sure that he is able to do that. That means we often assume all the responsibilities of the day because his health has prevented him from doing so, we are always there to provide him with the supervision he needs, and we take extra steps to make sure he can be there to watch his daughters riding in their rodeo circuits. Recently, I took on an additional job working from home so we could afford the type of horse trailer we needed to accommodate Cody's needs while out at the rodeo. I'm pretty sure my children's favorite thing to do is to drive their father to pick up his latest animal find from the farmers down the road, of course surprising mom!

I am no longer naïve; I know that there may come a day where I can no longer care for my husband safely in my home. However, I along with the thousands of other caregivers, should be allowed to make the decision that is best for our families. We deserve to do that with the full support of the Department of Veterans Affairs. My husband did not ask for this, he chose to defend our country without hesitation, unknowing the consequences of war that would impact the rest of his life. My family deserves the right to be supported in our decision to continue to provide care for my husband in our home because that's where he wants to be. Despite any disabilities and accommodations, if he chooses, my husband deserves to be involved as much as possible in our lives and not put away in a facility to be cared for by others. But we can't give him that choice without help. He nor any other combat wounded or injured Veteran asked for this role and it is this country's responsibility to ensure we provide them with unwavering, easily obtainable support.

Because of my lived experiences and experiences of other caregivers, I would like to make the following recommendations:

- The immediate passage of H.R.8371, Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act which includes a number of provisions to address the challenges I mentioned today including expansion of the Vet Directed Program, respite options, access to community care, an assisted living program if we eventually decide we need it, help navigating the VA's programs and services, and many more.
- Expansion of complex post-acute neurological treatment and research within the Veteran Health Care System.
- Grandfather all current PCAFC legacy participants. We have been through so many changes and pauses in this program—we have been found eligible many times before. Please let us get the support we need without having to prove ourselves over and over again.
- Provide easily obtainable case management or care coordination services for Veterans with complex medical needs to ease the burden for caregivers and promote better outcomes for veterans.

Thank you all for the opportunity to share my story. I share these personal details with you not looking for sympathy but to ensure significant positive impactful change, lessening the load for veterans and their caregivers across this nation.

Thank you,

Vanessa B. Chism

References

1. Goldstein LE, Fisher AM, Tagge CA, Zhang XL, Velisek L, Sullivan JA, et al.. Chronic traumatic encephalopathy in blast-exposed military veterans and a blast neurotrauma mouse model. *Sci Transl Med.* (2012) 4:134ra60.
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