WRITTEN TESTIMONY OF CAIRA BENSON, MILITARY CAREGIVER AND DOLE CAREGIVER FELLOW WITH THE ELIZABETH DOLE FOUNDATION BEFORE THE SENATE COMMITTEE ON VETERANS' AFFAIRS UNITED STATES SENATE ON THE VA'S PROGRAM OF COMPREHENSIVE ASSISTANCE FOR FAMILY CAREGIVERS

March 23, 2022

Chairman Tester, Ranking Member Moran, and Members of the Committee, I am pleased to testify today alongside Steve Schwab of the Elizabeth Dole Foundation on the VA's Program of Comprehensive Assistance for Family Caregivers.

When I first met my husband, Eric, in 2005, I never imagined what would lie ahead. I saw us raising a family together, thriving in our respective careers, and traveling the world together in our retirement. But after returning home from the frontlines of the Iraq War, Eric and I found ourselves preparing for a very different kind of battle.

Eric was a combat engineer officer in the Army. His overall plan was to serve for as long as he could and make a career of it, but his major injuries in the early 2000's would end that dream. I still remember him returning from Iraq in 2006, after continually being exposed to explosions and chemicals, and knowing things were "off." When he discussed this with his doctors, they would brush it off as "reintegration stress." No one would listen, even when my husband started experiencing numbness in his legs when he went running. Every symptom and complaint was ignored when no clear cause could immediately be found, even though both of his post-deployment screenings showed what I now know to be clear signs of a Traumatic Brain Injury (TBI).

It would take us a multitude of specialty clinics and countless doctor's appointments until he was formally diagnosed with a TBI in 2018. He was also formally diagnosed with Toxic Encephalopathy[1] the same year. This meant he was also facing a progressive neurological decline that was very likely caused by continuous blast and chemical exposures. By the time of diagnosis, my husband was using a wheelchair for long distances, blacking out, suffering from continuous headaches, and had been removed from all work due to employers being unable to accommodate his disabilities. He was only 38.

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[1] According to the National Institute of Health, toxic encephalopathy is "used to indicate brain dysfunction caused by toxic exposure. Toxic encephalopathy includes a spectrum of symptomatology ranging from subclinical deficits to overt clinical disorders. The clinical manifestations of toxic encephalopathy are related to the affected brain regions and cell types."

Today, Eric is considered wheelchair bound without hands-on assistance.[2] His daily life is interrupted by loss of fine and gross motor control, migraines, blackouts triggered by lights and scents, photophobia, and chronic regional pain syndrome. In addition to all of this, his current neurological degradation has begun to impact his eyesight and his ability to read. His level of disability and care needs qualifies him to be enrolled in Home Based Primary Care (HBPC) at the VA, in addition to seeing specialized neurologists.

Every day I, alongside our five children, watch him decline slowly from his TBI. Watching him understand his condition and coming to terms with the future is heartbreaking.

When we heard of the Program of Comprehensive Assistance for Family Caregivers in 2017, we were elated that there was finally a program that could support me with the new challenges we were facing. We were enrolled in PCAFC in 2017, but were discharged by the spring of 2018 because we spent winters with family to accommodate Eric's medical conditions. Despite having set addresses in both locations, we were discharged due to a "non-permanent address."

In October of 2020, the Final Rule for PCAFC was published. At first, I was delighted that the regulations had shifted to begin considering illnesses that were not service connected. Eric has been considered permanent and totally disabled since 2017, but since we were still struggling to service connect his TBI and Encephalopathy, I was optimistic this change would be able to help families like mine.

We applied the moment the new regulation went into effect. In fact, we were the first veteran/caregiver team to go through the new process at Lake Nona VA Medical Center in Orlando. Our HBPC team, and even the initial assessor, considered our case to be an "easy approval." Eric had a Katz score of zero, meaning he needed help with every single Activity of Daily Living (ADL), functional assessments documenting his ADL needs, and three providers on record saying he should not be left alone due to his blackouts, his confusion afterwards, and his newest symptom — a facial droop that caused difficulties with speech and swallowing.

Considering the plethora of documentation for his caregiving needs, his care team was shocked when our case was denied by the Centralized Eligibility and Appeals Team (CEAT) within days, and without even allowing the veteran's primary care physician to weigh in on the case.

I was livid. The reasoning of the CEAT's denial was that the RN who did Eric's functional assessment rated him as independent across the board—a direct contradiction to what we stated to the RN during that assessment and what was clinically documented. I assumed this would be easy to correct and immediately filed an appeal with the help of a patient advocate.

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[2] Hands-on assistance is defined as the physical assistance of another person without which a person would be unable to perform one or more of the Activities of Daily Living (ADLs).

We were denied again. I enlisted help in drafting our second appeal from the Quality of Life Foundation, and in doing so, unearthed even more discrepancies in our case. I filed the new appeal and was contacted by the Caregiver Support Program (CSP) to discuss the review. When I returned the call, I was shocked to discover that no one at the facility, local or VAMC, knew who the person who had called me even was.

I called the number on the appeals form and connected with the Program Manager of VISN 8 Caregiver Support who helped us track down our appeal letter. After digging into our case, she agreed our case had an "egregious oversight," that Eric's Functional Assessment was indeed "negligent." She couldn't override our denial at the local level, but she would help us by ordering a new assessment so it would reflect the medical record. In addition, she documented in his medical records that there had been a significant mistake in our assessments, as well as in our decision, and that those assessments had been redone to be consistent with the medical record.

After months of work and discussion with the VA, the Atlanta CEAT finally approved our enrollment within PCAFC. Despite Eric's doctor's requests to be placed higher, we were placed at Level One of the program. We should have easily qualified for Level Two, but we were tired of fighting the system and did not appeal the decision.

We stayed current in the program, conducted wellness checks, and continued to meet the parameters of the PCAFC program. Eric continued with his therapies and HBPC care. We had other battles we needed to tackle and were ecstatic that PCAFC was no longer one.

In December of 2021, we were called and told it was time for our annual reassessment. I was also informed that we would be going through the entire application process again, including an intake questionnaire. I was baffled. We did our check-ins and regularly met with his care team, so we were unsure as to why we needed to complete the entire process again.

On January 14th, we completed the first portion of our yearly assessment. Before we began, I made the assessor aware that my husband had medical accommodations in place due to his TBI. If Eric spends more than 30 minutes engaging in sustained cognitive tasks, his left face starts to droop, he starts to slur words, and he loses the ability to swallow. Eric also had just been discharged from the hospital due to complications from COVID-19, and the assessor and I both agreed on the importance of not pushing Eric to exhaustion.

Despite this, the assessor continued the assessment beyond his accommodative limit and Eric's face began to droop. I began to help answer questions surrounding his history in order to give him a break, but the assessor insisted she needed the answers from him and if I didn't stop interjecting, she would make me leave the room. I reiterated his need for a shortened assessment to accommodate his condition, but she told me she was unable to split up the assessment.

After nearly an hour of questioning, I decided Eric needed to stop. He was losing the ability to speak, had a migraine, was short of breath, and even had drool coming out of his mouth from his inability to swallow. He had become so exhausted that he couldn't hold himself up in his wheelchair, and his entire left side was unresponsive. I helped lift him into bed, gave him much needed migraine medication, and continued the assessment alone as he slept.

We went on to thoroughly discuss Eric's ADL and IADL[3] needs. Despite these needs being recorded in detail in his record by his HBPC team and despite everything that the assessor had just witnessed, it seemed as though the assessor did not believe me and challenged me on why he needed assistance. However, nothing could have prepared me for what I was asked next.

The accessor then asked if I had "any concerns about [my] intimate relationship." I was stunned. When I clarified to see if she was asking about intimate partner violence, the assessor reiterated that she was specifically asking about intimacy issues. Not only did this have no relevance to his condition or caregiving needs, but it was also humiliating and demeaning.

After a little over two hours, the assessment concluded. This was followed up with three more assessments the next week, all of which took no less than an hour, and were scheduled around his nine regularly scheduled appointments and therapies. We were approved to remain at the lower level within the program for assistance with two ADLs, despite his care team documenting him needing assistance with five ADLs and his inability to be left alone. It is especially worth noting that he was not approved under Safety, Protection, and Instruction. This qualification is part of the new regulations, and is supposed to help caregivers who assist with mental health, neurological residuals, and IADL needs qualify for the program. Eric's need for non-ADL support, even though clearly documented in assessment and medical records, was never even taken into consideration during CEAT decision.

When I first heard about this program, I was so thankful there was finally assistance for caregiving teams like Eric and me. I needed someone to be a resource for us and to support our unique needs. Sadly, I was let down. I am disheartened and dismayed at what this program has become.

Unlike thousands of caregivers going through the same process, we are still in the program. However, the past five years we have spent interacting with the program have been

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[3] According to the VA, Instrumental Activities of Daily Living (IADLs) are defined as "a series of more complex tasks or functions that help maintain one's personal life and environment, for example: shopping for food, cooking, doing laundry, housecleaning, managing money, managing medications, driving/using public transportation, or using the phone."

demoralizing, humiliating, and exhausting. Those years have also taught me that this support can be taken away at any time. A truth validated by watching so many other deserving families being discharged right now.

This yearly process takes hours from our lives—hours I need to support Eric. Eric has felt so demoralized by the program and the processes involved. The VA's mission is to care for those who shall have borne the battle, yet Eric feels they are ignoring a crucial part of that mission and his healthcare if VA is not fully supporting the caregiver. Given everything we have gone through, and Eric's feelings of betrayal, we are currently weighing if the benefits of this program are worth the physical and emotional toll it takes on our family. This cannot have been the intention of Congress when it was passed unanimously years ago.

I am not alone in this experience. Across the country, there are thousands of Cairas and Erics fighting for support from the VA. The PCAFC process needs to be simplified and the assessments need to be less frequent, intrusive, dehumanizing. Our HBPC doctors already document much of what is asked by the caregiver support program during assessment. VA doctors should have templates ready to document what is needed for the CEAT during appointments. Neurological impairments and IADLS should be properly weighed under the supervision, protection, and instruction qualifier. Progressive or long-term cases, like Eric's, should be allowed a respite from yearly assessments as long as his HBPC team verifies there is no significant improvement. It is time for the Caregiver Support Program to truly accommodate their participants.

It is my privilege and honor to be Eric's caregiver, and my worth as a caregiver is not defined by my acceptance into, nor my participation in, any program, especially including PCAFC. However, the quality of my husband's care at VA is, and should be, judged by how VA treats, supports, and deals with veteran caregivers.

Chairman Tester and Ranking Member Moran, thank you for holding a hearing on this critical issue and allowing me to share my story. I am happy to answer any questions you may have.