STATEMENT OF PETER TOWNSEND

BEFORE THE

THE SENATE SPECIAL COMMITTEE ON AGING

AND

THE SENATE COMMITTEE ON VETERANS' AFFAIRS

ON

"HEROES IN THE HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS"

JUNE 5, 2024

Chairman Casey, Chairman Tester, Ranking Member Braun, Ranking Member Moran, and distinguished members of the Committees. Thank you for the opportunity to speak with you today regarding my experiences with the caregiver support services available through the VA and its Caregiver Support Programs.

My name is Peter Townsend. I'm currently 60 years old and live in Auburn Township, Susquehanna County in northeastern Pennsylvania with my wife Lisa, who is also my caregiver.

I served in the United States Army on active duty from 1982 to 1986. After completing infantry and airborne training, I was assigned to units in Ft. Lewis, Washington, Camp Kitty Hawk in the Republic of Korea and Ft. Bragg, North Carolina.

Following my discharge from active duty in 1986, I used the educational benefits I earned through the Veterans Educational Assistance Program to pursue an education in healthcare and earned degrees in nursing and as a Physician Assistant. I went on to work for over two decades as a Physician Assistant, mostly in primary care, before retiring prematurely in 2014 due to complications of Primary Progressive Multiple Sclerosis.

When I was initially diagnosed with Multiple Sclerosis (MS) around 2007, my symptoms were mild and progressed slowly. Unfortunately, as the disease progressed, I began to experience significant difficulty with mobility, as well as difficulties with fatigue, cognition and bowel and bladder dysfunction, among others. Today, I rely upon a power wheelchair when out in the community and a walker to ambulate short distances in the home.

Through casual conversations with fellow veterans, I learned that MS was a medical condition that the VA recognized as a presumptive, service-connected disease.[1] At the urging of my veteran friends, I filed a claim with the VA for disability in 2019. With the assistance of Paralyzed Veterans of America, of which I am a member, I was successful with my claim and am now rated 100 percent service-disabled due to MS. After receiving my determination, I enrolled for the first time in VA healthcare.

As my symptoms progressed, I began to rely more and more on the assistance of my wife, Lisa. My experience with MS has been that of unpredictability with a wide variation in symptom severity. Most days are "good days" where I am able to function fairly independently. However, when confronted by a flair or "pseudo exacerbation," often as the result of a febrile illness or other acute condition, I can become temporarily incapacitated. During these times, I rely very heavily on Lisa for assistance with a variety of activities of daily living to include intermittent catheterization, transfers, toileting, personal hygiene, dressing and meal preparation. Fortunately, these episodes are infrequent and short-lived, lasting from several days to a week or two. Even though infrequent, I have had no less than three of these episodes already this year.

Prior to leaving the workforce, Lisa had been working as a Case Manager for Keystone Community Resources in Montrose, Pennsylvania, a company that provides services to adults in the community with intellectual and developmental disabilities. Eventually, as my condition deteriorated, we decided that Lisa would

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[1] VA Benefits and Services for Veterans with Multiple Sclerosis - Multiple Sclerosis Centers of Excellence

retire early from her position in June of 2022 at age 61, in order to be my full-time caregiver.

Once again, primarily through a process of self-education and online resources, we learned of the VA’s Program of Comprehensive Assistance for Family Caregivers (PCAFC). So, when the VA opened eligibility for the program to veterans of all service eras in October 2022, we applied. Unfortunately, we were informed the following month that our application had been denied. As I understand it, we were denied entry into the program due to the VA’s determination that I did not require assistance with the performance of certain “activities of daily living” each time that activity was performed, or that the level of assistance did not “rise to the level required to participate in the PCAFC”.

This strict interpretation of the eligibility criteria by the VA is of particular concern to veterans like myself with medical conditions like MS whose symptoms are highly variable and unpredictable. My concern is that because of this current interpretation by the VA of the eligibility criterion for the Program of Comprehensive Assistance, many other veterans like me and their caregivers are being denied access to this extremely valuable program. I’m confident that I am not the only one!

After our application for the comprehensive program was denied, Lisa was eventually enrolled into the Program of General Caregiver Support Services (PGCSS). However, this transition to the PGCSS was not automatic and we went for some time thinking that we were enrolled in the general program, although we were not.

One of the most valuable benefits of the Program of Comprehensive Assistance, is the availability of medical insurance coverage for caregivers through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA). The availability of CHAMPVA was the only way we could afford for Lisa to retire early and fortunately for us, she qualified for coverage under the program due to my permanent and total disability rating. This option, however, is not available to those veterans denied Access to the PCAFC, whose disability rating is less than 100 percent, permanent and total.

Although the Program of General Caregiver Support Services offers fewer benefits than the PCAFC, one significant benefit it does offer is respite care. We were able to utilize this benefit earlier this year when Lisa underwent total knee replacement surgery in January. The Spinal Cord Injury and Disorder (SCI/D) Clinic Coordinator was able to arrange for me to be admitted to the Community Living Center at the Wilkes-Barre VA for three weeks while Lisa recovered from her surgery. Lisa knew that regardless of what was happening with my health, I was being cared for so that she could focus on her recovery. I can't emphasize enough how valuable the respite care benefit was to our family at that time, and it's comforting to know that it will be there if we need it in the future.

Throughout this journey, our goal has been, and will continue to be, to create an environment that allows me to live in our home as long as possible and to avoid the need for long-term care. Participation in the VA Caregiver Program helps us to achieve that goal. The reality is that my current level of disability is such that I am no longer able to live independently and would require placement in an assisted-living facility were it not for Lisa's efforts.

I would like to make it clear that Lisa and I remain very grateful for all the benefits that we have received and continue to receive! These include, but are not limited to, the Home Improvements and Structural Alterations (HISA) grant that we used last year to partially fund the complete remodel of our master bathroom to make it fully wheelchair accessible, as well as other grants and services that I am eligible for but have yet to utilize. We thank the Veterans Administration for the services that they have already provided and the excellent care that I continue to receive.

One of the ways that I am able to show my gratitude is by volunteering at the Wilkes-Barre VA Medical Center. For over two years I have served as a Red Coat Ambassador, once a week, as a way of serving my fellow veterans and by giving back to the organization that has done so much for me.

The system is not perfect, however, and there will always be room for improvement. I encourage the committees to work with the VA to ensure a more seamless transition to the PGCSS following denial of the PCAFC. Also, there needs to be better communication to veterans of the resources and benefits available through the VA, particularly those newly enrolled in VA healthcare. Lastly, taking care of a loved one is work, and caregivers should be treated that way. Congress needs to pass legislation like the Social Security Caregiver Credit Act of 2023 (S. 1211) which would give Social Security credit to caregivers who have left the workforce prematurely to care for their loved ones.

Finally, as a member of PVA, I would be remiss if I did not mention the need for Congress to pass the Elizabeth Dole Home Care Act (H.R. 522/S. 141) which will further improve upon the resources and services available to veterans like myself and their caregivers. This legislation addresses some of the most urgent needs of veterans and the people who care for them, and they should not have to wait any longer. I urge you to pass this bill as quickly as possible.

I thank you for this opportunity to share our experiences and look forward to answering any questions that you may have.