Statement of

Kathleen Swinbourne, Family caregiver to

Navy Retired Vietnam Veteran, Clare John Swinbourne

Before the Committee on Veterans' Affairs

United States Senate

On Long-term care for Veterans in Maine

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Good afternoon, Senator King, thank you for the opportunity to participate in this Senate Veterans Affairs Committee field hearing on long term care services for veterans in Maine. My name is Kathleen Swinbourne and I'm from Topsham, Maine. I'm a Registered nurse in the State of Maine, License massage therapist, longtime yoga instructor and business owner. I'm here to share my experience as a family caregiver for my father, Clare John Swinbourne, an 85-year-old Navy veteran with 20 years of service and three tours in Vietnam. My dad was exposed to Agent Orange; and suffers from Parkinson's dementia and PTSD.

In 2012 my dad was diagnosed with Parkinsonism symptoms and from the instruction of a family physician he was encouraged to apply to the VA for disability but was denied due to the diagnosis "Parkinsonism" rather than Parkinson's disease.

My active care for my dad began in 2019. At that point, my dad had been living with Parkinsonism symptoms for 7 years. His gait was off, and he walked with a cane. He was struggling with his executive function and experiencing intense mood swings and long bouts of depression. One day in December of that year he suggested we hang outdoor wreaths at my parents' home. We walked to the front of the house, and he gestured for me to walk ahead of him. He was often self-conscious of his slow and laboring walk. I went ahead and in moments I was startled by his yells behind me. I turned to see my dad lying on the ground with blood on his hand and knee. I ran to help him. I could tell by the blood and shock in his eyes that he had no warning that his body was going to give out on him. He was embarrassed and apologetic and I helped him to his feet. I put my arm in his and aborted the wreath hanging to lead him inside to care for his wounds. We walked down the driveway to the garage, and he took one step into the door and we both crashed down on the cement. My dad landed on the same bloody knee and hand. The fall happened so quickly, I had no opportunity to brace myself or protect him from falling. This time, he was sobbing and in shock. I held my dad for a long time as he cried. I can't say I knew how he felt, but I realized with him that the Parkinson's disease was progressing and the body he knew and trusted his whole life was beginning to betray him.

I eventually got him to his feet. Inside I cleaned and dressed his wounds and settled him on his comfy recliner. All the while he apologized for falling, which I told him wasn't his fault. Once I got him settled, I went downstairs in a separate room and cried uncontrollably. I sat there for a long time crying and praying. I knew I needed to figure out how to care for him with this disease and felt overwhelmed.

The next day I called his primary care doctor and reported the event and requested urgent assistance with my dad's mobility and safety. His doctor put in a referral for homecare. Within a day Chan's of Maine came to my parent's home. The process began with a social worker who interviewed my parents and I and assessed my father's needs. At the end of the conversation the social worker took me aside and explained that her organization can help my dad, but since he was a veteran, she felt he would get better care through the VA. She spoke highly of the VA and all the services offered to veterans. She told me it would be very difficult to get his disability and will become a full-time job. She cautioned me that I may feel like giving up during the pursuit, but don't. The social worker was right about everything!

I followed her advice and immediately pursued my dad's disability with the American legion at the VA in Togus, Maine. We submitted the application and then attended many medical appointments to fulfill the requirements. Two months into the process the pandemic began. Consequently, appointments were cancelled, and I was regularly and persistently trying to reschedule them. It took about a year to complete this and finally my father was determined to be 100% disabled in August 2021. As soon as my dad's disability was granted, we applied for readjudication of his benefits under the Nemer Settlement.

During the year of pursing his disability I had many conversations with the American Legion representative. I felt overwhelmed with my dad's care needs and uncontrollable rages due to Parkinson's dementia. Falls were happening more often, and I felt ill equipped to manage the progression of his disease and maintain harmony at my parents' home. The representative suggested I call the VA help line for caregivers, so I did. The trained worker on the line calmly listened to me as I cried and tried to explain the stressful circumstances of caring for my dad with this degenerative disease. At the end of the call this kind woman connected me directly to a social worker at the VA Togus who was part of the Family caregiver program. I will never forget this conversation as it brought me a feeling of hope that I wasn't alone and there are resources at the VA to help families care for their loved ones. She told me about the family care giver program and how to apply to be a paid caregiver. I quickly applied and after a few months was accepted into the program in March 2021 as a stipend part time caregiver. I took advantage of counseling for caregivers and joined many support groups to learn as much I could about Parkinson's dementia. Through her guidance I enrolled my dad in the healthcare system at the VA and gradually moved his medical care from the community to the VA throughout the next two years.

Based upon what I was learning I realized the need to handicap my parent's home, so I applied for a grant at the VA to do this. This process was almost as arduous as applying for his disability. I needed to coordinate with outside contractors to give me estimates for construction. I had to meet with a VA contracted physical occupational therapy practice who assessed the needs at the home. They wrote up an assessment and faxed it to my dad's primary care at the VA and then I waited months for a reply. I kept calling primary care and they told me they hadn't received a fax. Then I would call the physical therapy practice and they insisted they sent it. After this back and forth went on for two months I asked to speak with the manager at the practice and she said she had a contact at the VA and would get to the bottom of this. Turns out, a form was being faxed numerous times, but it wasn't the right form, and this wasn't being communicated to them nor me. As soon as the form was corrected the VA evaluation began and I submitted a detailed application for the grant. Once the grant was approved in a few months I then hired outside contractors to do the work and after almost a year we installed a handicap shower, wheelchair ramp, stair glide, widen doors and grab bars throughout the home.

In February 2022 we hadn't heard a response from the claim we filed a year before for the readjucation. I called our American Legion representative many times to receive the same response, it hasn't been processed yet. I then contacted Senator King's office for help on this delayed response to my dad's claim and within two weeks my dad's application was located and he received his back pay, which we immediately began to use for a paid part time caregiver we hired. My dad's needs were steadily increasing, and both my mom and I were feeling the mental, emotional and physical stress of caring for my dad around the clock seven days a week. Even though I was a paid part time caregiver this wasn't enough for me to live off, so I simultaneously pursued nursing school with the intention of caring for my dad. I also began to investigate into ways for more help from the VA. I applied for full time status with the caregiver program and was denied. I attempted to call the Vet direct care program over 50 times in a few months and never received a call back. I called my caregiver appointee and director of the caregiver program numerous times desperately asking for more assistance. I was informed it maybe time to look at nursing homes for my dad, but we didn't want to do that. I felt if we could get more money for home care, we could make it work. As my dad's dementia increased this quickly showed us, we were in this over our heads as he kept calling 911 during mental rages and bouts of agitation. After numerous ER visits and eventually a hospital stay it was recommended, he enter a rehab facility. During rehab he received the maxumus assessment and was assessed at long term care. Miraculously a bed opens at MVH in Augusta and my dad was moved into one of their wings.

MVH is a beautiful facility and has amazing offerings: a chapel, theater, gym and pub with regular events and live music. To me and my family it was a Hilton hotel for the elderly. However, with my dad's severe and unmanaged dementia it was scary for my dad to be there. His current condition needs constant care. His change in personality and temperament is often unbearable to be around for staff members who aren't trained to manage his disease and these circumstances created a lot of stress for him, their staff and our family. He repeatedly threatened to leave and would regularly tell me he was terrified to fall asleep at night because he thought the staff was going to hurt him. We tried to reassure him, but its difficult to rationalize with someone who has dementia. I had regular conversations with the primary care team at MVH to figure out how we could create more ease for my dad and address why he was being told he could stay or go at will. To my family and I we knew he didn't have the capacity to make his own decisions, but I was informed by the primary care team at MVH that they didn't want to the be the ones to initiate taking away his right to decide and our family similarly was apprehensive. MVH reached out to my Dad's VA primary care team at the height of my dad's threat to leave and the social worker was able to speak with my dad and then contacted me. It was clear to both of us my dad was ill equipped to think rationally. This was before Christmas, and I was told that the primary care team was going to meet and figure out the next steps. I still haven't heard back. Two days before Christmas my dad called a cab at MVH. The staff called my 84-year-old mom and she drove to pick him up. With his dementia mind he promised my mom he would return to MVH after Christmas. Unfortunately, when the time came, he refused to return. Without proper medical guidance we ended up feuding as a family trying to figure out our next steps. We were told he couldn't return to MVH as he exceeded his allotted days away, but we didn't know who to turn to. After a couple of uncomfortable days for my dad he ended up back in the local ER and eventually transferred to the Togus ER and is now in Long-term care at Togus VA.

My siblings and I have many conversations trying to figure out what we could've done differently. As much as we loved MVH it wasn't the type of skilled setting my dad needs for advanced Parkinson's dementia. When I visited him at Togus the first thing he said to me was, he feels safe there. He's monitored regularly by doctors and nurses and the setting is more controlled for his current needs. I recognize that chaos can eventually lead to order, but walking alongside him through this difficult disease has truly been a grueling process.

I'm here today to share my story to tell others caring for Veterans, to not give up. I'm also here to share the things that I feel need improvement at the VA. I'm so happy with the benefits we've received. Even though many times it felt like I was trying to break down a brick wall, once the wall came down, I was able to tap into a wealth of resources for my dad and myself to support his disease process. I wish I had a case manager or medical social worker to guide me through the appropriate channels and check points to regularly evaluate my dad's condition and needs and to make sure his medical records were always up to date and to help us move through the stage from being at home to nursing level of care. I know this is the intention of the VA to provide a medical social worker and we were assigned one, but this wasn't our experience, and it was very difficult for me to connect the primary care team with the caregiver program and it was also challenging to know the path to follow and the steps to take and to get a call back from the social work team. We often fall upon the next steps through crises. I was regularly asking for help, but so often my phone calls weren't returned. When my dad went into rehab, I was undergoing an extensive months long process to re-apply for full time caregiver status as well as Vet directed care. By the time there was a decision my dad simultaneously was admitted to the hospital. Why is there such a long wait to apply for support? I realize there's a staffing shortage but meanwhile families and caregivers are suffering trying to care for the veterans with little pay. It's a huge sacrifice and although my father chose to serve in war, my mother and I didn't yet we've been paying the price for my dad's war related disease as I've given up virtually my 40s to care for my dad and my mother has compromised her own health in the process.

In an ideal world veterans and families would benefit from a medical social worker to educate them on the process of the disease and its progression and guide them through the proper channels in moving from the home to nursing level care. Additionally, the medical social worker can bridge the families to the providers for regular geriatric evaluation and management and the care giver program upon immediate diagnosis of a war related disease. The VA has all the big pieces that can help. It's the little stuff, connecting the dots between the programs, where things fall apart.

I'm so grateful to your office Senator King, as I regularly contacted them for assistance when I was unable to receive return calls and clear guidance from the staff at the VA. I'm certain the support of your office is what allowed me to experience progress and momentum in my dad's care. However, I don't feel veterans and families need to take it to this level. Calls should be returned. Guidance needs to be available, and the application process is too extensive for aging veterans who don't have a young family member or advocate who can give up their job to pursue their benefits and care. For five years I temporarily gave up my career and income for my dad, because I love him, and I believe in honoring those who fought for our freedom, but I've greatly compromised my financial, physical, mental and emotional stability due to the constant stress and time of this commitment. If I had been compensated for caring for his full-time needs, I may feel differently but I was doing full time work for part time pay and balancing nursing school to responsibly pursue a line of work I was hoping to use in the care of my dad. I believe the VA is a wonderful organization with an abundance or resources for families and veterans and I'm hoping that the refinement of better communication and correspondence and leadership from the primary care team can created positive change for veterans and their families.