STATEMENT FOR THE HEARING

QUALITY OF LIFE FOUNDATION

FOR THE HOUSE COMMITTEE ON VETERANS AFFAIRS

HEALTH SUBCOMMITTEE

CARE COORDINATION: ASSESSING VETERANS' NEEDS AND IMPROVING OUTCOMES

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Madame Chairwoman, Members of the Subcommittee, my name is Andrea Sawyer, and I am the Advocacy Director for the Quality of Life Foundation (QoLF), a national non-profit organization founded in 2008 to address the unmet needs of caregivers, children and family members of those who have been wounded, ill, or injured serving this nation. Since then, we evolved and now work directly with veterans and caregivers as they attempt to apply for and navigate the Program of Comprehensive Assistance for Family Caregivers(PCAFC) and other clinical support programs within the Department of Veterans Affairs. Serving all generations and focusing mostly on those with significant wounds, illnesses, or injuries, we often assist those with the most complex needs.

As one of the few organizations working exclusively within the Veterans Health Administration, and as a caregiver to a Post 9/11 veteran myself, we have had a front row seat to witness and help others utilize many of the programs and services available within the VA. While we do NOT provide clinical recommendations of any kind, our role is to ensure that veterans and caregivers are prepared for the PCAFC process, assist in the drafting of clinical appeals to ensure the VA is following its own regulations and directives, and assist veterans and caregivers in navigating other programs and supports available to them.

In that role, we see the positive things that can happen when veterans and caregivers are connected by caring and passionate providers and social workers to the programs and services that enhance their care and their quality of life. PCAFC, Respite, Veteran Directed Care, and the Homemaker Home Health programs are just some of the programs that support veterans in their homes and can serve as a lifeline for veterans in need. Unfortunately, we also see what can happen when

those especially vulnerable veterans are not connected to those resources, and, more often than not, poor or a complete lack of care or case management is at the root of the problem.

In order to understand the problem, it is important to understand a little bit of the history and terminology involved in this process. After the Walter Reed scandal, the Department of Defense and the VA stood up unprecedented levels of case management for injured veterans. At one point, it was not uncommon to hear family caregivers say that we needed a case manager for our case managers, ultimately resulting in the creation and implementation of the Federal Recovery Care Coordination program for those with multiple severe injuries and complex needs. FRC's were Masters Level GS-15's nurses or social workers reporting to the Deputy Secretary with broad referential authority and, in the best of cases, the ability to created integrated care plans and cut across program and agency lines to resolve issues for the most vulnerable warriors and their caregivers.

Since the winding down of operations in Iraq and Afghanistan and even before then, however, the case management programs seem to have been minimized with some being removed, some being revamped, and still others being renamed. Unfortunately, the case managers seem to have all again been siloed in their efforts. While FRC's still exist, there are very few of them and they have been relegated further down into VHA and do not interact with veterans directly. Instead, they serve as consultants upon request of the facility, when and if the facility knows to call them—leaving those with the most complex needs, a population that includes severe mental health issues, PACT act eligible veterans, and those with long-term complex injuries and conditions with no known case manager who can help them navigate resources across the VA, access the Community Care Network, and develop a workable coordinated care plan.

Every veteran in the VA is entitled to care coordination; this is basic care coordination through the Primary Care Manager and a basic treatment plan that the veteran is responsible for carrying out.

In our experience at QoLF, we see many veterans with care managers—people who usually manage one clinical support or disease specific program—but no overall case manager. A care manager does not necessarily look at overlapping needs or outside the clinic in which they are operating.

Care objectives in disease specific treatment plans may be contradictory OR multiple disease/injury specific care plans may create an overall higher burden on

the veteran and caregiver for management. With no higher oversight on the part of individual care managers, veterans and caregivers have multiple plans to try to navigate and multiple points of contact individual to each disease, injury, or intervention.

Many of the veterans that QoLF serves have complex care needs. They are in need of case managers. Case managers are trained to evaluate the multiple care plans that a veteran has for each injury or condition, look at the veteran's whole health needs— including environmental and social needs, and develop a coordinated care plan. The coordinated care plan will take into account each condition, set goals or targets for each condition, list who is responsible for those goals/conditions, and set target dates for completion. This gives the veteran and caregiver ONE point of contact for issues that arise. Cases that need case management are time-intensive, require coordination of care both inside and outside the VA, and usually have psychosocial and environmental needs as well.

In Ohio, we were contacted by an elderly veteran who had been removed from the Caregiver Support Program. The veteran had been in Home Based Primary Care, the Caregiver Support Program, and was receiving support from Geriatrics and Extended Care. The caregiver was using her stipend to pay for in home physical therapy, occupational therapy, and extra homemaker home health aide hours. When it was time to review the veteran, the caregiver was removed from the Caregiver Support Program because the Caregiver Eligibility Assessment Team felt that by removing the caregiver from the program, then the caregiver could be given many more hours of support by Geriatrics and Extended Care, something that is prevented by a case matrix tool that exists between GEC and PCAFC.

However, and this is where case management would have been helpful, upon the removal of the caregiver from the stipended portion of the VA Caregiver Support Program, there were no steps put in place to immediately increase the veteran's hours of care through Geriatrics and Extended Care. Nor did VA send or coordinate more physical therapy or wound care therapy at the home of the veteran which had been being paid for by the caregiver from her stipend. The caregiver began calling the local non-emergency line to help change and bathe the veteran after no home health care workers were initially added to assist the caregiver. Additionally, the caregiver suffered an increasing level of exhaustion, as the VA contracted workers failed to show up for more than half the hours for which they were contracted and the workers were a revolving door of workers, some of whom did not speak any English in an only English speaking home.

Once we asked for a higher level of case management to engage with the VA, there were a higher number of hours that were granted for homemaker home health aide hours, but they still were not filled. The issue became that GEC said it was the agency's responsibility, and the caregiver was supposed to take it up with the agency; the agency said they did not have workers to fulfill it, and no one was able to support the caregiver and veteran in their ever declining state.

When we first got the family, the veteran and caregiver needed more support, but due to a lack of coordination between PCAFC's dismissal and GEC's ability to actually get the necessary about of services into the home that had been being provided by private care with the caregiver stipend, the people who paid the price were the veteran and caregiver. Unfortunately, while the hours were raised, they were still unable to be met, and now the veteran is in the hospital. Had VA coordinated the proper order of resource stand up and withdrawal, this case may have had a better outcome. This is where an overall case manager would have been helpful in aligning the order of how resources could have been added and removed.

Additionally, no one is assisting the veteran to navigate Community Care Network referrals and records management. This falls to the veteran and caregiver, and those with these complex needs often cannot do it because it involves multiple behind the scenes VA processes and offices. Being a veteran with complex needs or an overwhelmed caregiver often leads to complications in the veteran and caregiver's social, emotional, and financial well-being. Having holistic long-term case management and a case coordination plan allows an extra level of support and management to improve the whole health of the veteran and caregiver so that they can focus on simply getting through treatment and recovery when possible.

In Arkansas, we have a 34 year old veteran with a cancer that has necessitated the removal of is colon and rectum, severe PTSD that has resulted in a behavioral flag being placed for outbursts, and a recent diagnosis of sarcoidosis of the heart, lungs, and intestinal tract. The veteran has additional complications of a severe allergy that permeates his diet, nutritional and medicinal absorption issues due to his missing colon and rectum, and social and environmental factors that include a distrust of the medical system. The veteran has five children aged 16 to 1. Complicating the care management, is that the veteran has had 15 VA PCMs in the six years that Quality of Life Foundation has had this case. He has multiple outside providers, some Community Care Network appointments and some providers that he uses his Medicare to see, because often VA does not have a timely appointment and referral process for him. His wife has never been accepted into

the VA Caregiver Support Program, and she works from home full time. Up until recently, the family had had no case manager.

After attempted conversations with the facility and then with VACO, a case manager was appointed through the M2VA office. Unfortunately, the case manager is more a care manager. He is not used to working complex case management that involves multiple conditions. The case manager is hampered by the delay in CCN notes being returned to the VA. The case manager is also assigned this veterans care on top of a very large population that he serves simply for care coordination and care management. When seeking answers about referrals or pieces of information, or trying to get two doctors to have a discussion about a patient, he has no authority to do so.

We have attempted to engage, through VACO and this committee for multiple years, a complete care coordination and case management plan. That has yet to happen. In fact on multiple occasions, my staff member has been told that the case manager, assigned by VACO at the local level, does not know how to do such a detailed case plan. As a result, the veteran's care lags, referrals fall through the cracks, the veteran's health declines, and an overall sense of dissatisfaction with VA healthcare and anger over feeling discarded permeates his life. The caregiver is angered that she has a management of the case manager that has to occur when she already has such a heightened responsibility. Overall the LACK of case management on a continued basis has caused the VA to fail this patient.

We understand that the VA is implementing a new process to appoint a "lead coordinator," and as part of this initiative is specifically looking at sites to further enhance the coordination of care through the Community Care Network. While we have some concerns that the lead coordinator role would not alone be sufficient to address these most complex cases, it will be helpful to have a named individual who is accountable for the provision of services. Our most pressing concern is that the lead coordinator position becomes a collateral duty on top of an already heavy case load. **As the "lead coordinator" process develops, QoLF recommends that the Subcommittee and the VA consider the following:**

The establishment of a cadre of specially trained case managers, similar to the FRC program and potentially linked to the lead coordinator who can take on the most difficult cases would benefit the individual veteran as well as free up the care managers and other case managers to serve more veterans. While most veterans can be accommodated by a simple phone call to a social worker or care manager, those with the most complex needs often need an individual with the training,

competency, desire and authority to request waivers, explore options, and develop integrated care plans

The establishment of a case management and social work lead at the VISN level who could help to coordinate training, standardization of services, and serve as a point of contact when challenges arise.

Ease the process of obtaining a case manager. While we have hopefully made a good case for having a case manager for those who need it, the fact remains that it is difficult to obtain one and very little public information exists to educate the patient. For example, the Richmond,Virginia VAMC homepage only mentions case management once as a subheading for Post 9/11 M2VA Care. There is no mention of co-morbid complex care case management or of disease specific case management. If you click on Post 9/11 M2VA case management, the description is not about multiple disease/condition/injury care, but more a description of transitioning back into civilian life after serving in the military. For those veterans that entered Afghanistan in 2001 or Iraq in 2003, should they look for case management services for multiple complex care needs, the description would not be one that would likely cause them to connect with the M2VA program or case managers. For any other veteran, not post 9/11, there is no mention of case or care management programs on the front page for that facility. So how exactly does a veteran know that these programs exist, know to ask for them, and know how to find them?

Review the current process for entering records from outside providers (CCN, TRICARE, Medicare, other private providers) and how it impacts the ability to provide appropriate care and care management. (This should occur system wide as the process varies facility to facility and VISN to VISN.) While reimbursement for care is an issue, the lack of a transparent process, including identifying who is responsible for obtaining the records and the methods by which those records are or are not uploaded into the VA system, delays care and frustrates both doctors and veterans. This lack of record input and management impacts patient care, eligibility for programs, and the care manager's ability to effectively manage the case.

Review the current <u>actual</u> caseloads of the different care management and social work teams across the VA to ensure proper staffing and allow for incentives to fill needed vacant roles. In addition, identify collateral duties that do not have a designated full time employee (FTE).

Establish a "Pathway to Advocacy" for outside organizations to officially assist veterans and caregivers within VHA. QoLF strongly supports the recent Senate introduction of the CARE Act of 2023 which includes a provision requiring the Secretary to develop a process to train and recognize non-profit organizations to assist in the navigation of programs and services within the Veterans Health Administration. While QoLF currently uses Releases of Information to advocate on behalf veterans and caregivers, such a process would allow certified organizations to work more effectively WITH social workers and care managers to better support the population we all serve.

In conclusion, Quality of Life foundation believes VA needs to simply re-align their resources and bring back older, more robust models of case management for those most severely impacted veterans. These program models have existed in the past, and for some reason were changed as the more recent conflicts wound down. As a result, care management was siloed and veterans suffered. Correctly modeling, training, and assigning case managers to complex cases would save time, money, and resources. Allowing VSO's and NPO's to advocate for care that exists within the system would also help veterans and facilities. Veterans would get more timely appropriate care with the help of a holistic full-time case manager with authority to cut through VA red tape. Overall, this would save VA money if the veteran is able to get timely, appropriate care that is managed across the spectrum of the medical community; and veterans would have better health outcomes and quality of life.