

# Caregiving in the Military Community: A Comprehensive Analysis of Challenges, Support Systems, and Lived Experiences

## Executive Summary: The Hidden Heroes of Our Nation

The well-being of the United States' military community extends beyond the uniformed service member or veteran to include a vast and often-overlooked population of caregivers. These individuals, aptly termed "Hidden Heroes" by the Elizabeth Dole Foundation, provide critical, round-the-clock support to their wounded, ill, and injured loved ones. This report synthesizes key findings from recent research, policy documents, and first-hand accounts to illuminate the unique landscape of military caregiving. The scale of this community is substantial, with an estimated 14.3 million military and veteran caregivers nationwide, representing 5.5 percent of the U.S. adult population.<sup>1</sup> The value of their unpaid care is immense, contributing an estimated \$199 billion to \$485 billion annually to the national economy, a service that would otherwise necessitate significantly greater government expenditure.<sup>3</sup>

Military caregiving is distinct from its civilian counterpart due to the prevalence of "invisible" conditions, the demanding military lifestyle, and profound barriers to help-seeking. While the challenges are formidable, a multi-tiered ecosystem of support has emerged, comprising a complex network of government programs from the Department of Veterans Affairs (VA) and the Department of Defense (DoD), complemented by a robust landscape of non-profit and private sector organizations. Despite the existence of these resources, a significant portion of caregivers remains unconnected to the benefits and community support to which they are entitled. The following analysis defines the scope of this community, details its unique burdens, and outlines the critical support systems available, concluding with an emphasis on the continued need for recognition, advocacy, and streamlined access to care.

## Chapter 1: Defining the Landscape of Military

# Caregiving

## 1.1 The Quantifiable Impact: Hidden Heroes in Plain Sight

The formal recognition and study of military caregiving as a distinct and significant national issue is a relatively recent development. Groundbreaking research conducted by the RAND Corporation in 2012, commissioned by the Elizabeth Dole Foundation, first identified 5.5 million Americans serving as military and veteran caregivers, providing an estimated \$15 billion in unpaid care annually.<sup>4</sup> This initial report served as a catalyst for a decade of focused advocacy and research, which culminated in the release of the 2024 follow-up study, "America's Military and Veteran Caregivers: Hidden Heroes Emerging from the Shadows".<sup>2</sup> This more recent analysis, sponsored by prominent organizations including the Wounded Warrior Project and AARP, provides an updated and more comprehensive view of the caregiving landscape.

The new data presents a dramatic increase in the estimated number of caregivers, now standing at 14.3 million individuals, comprising 5.5 percent of the U.S. adult population.<sup>1</sup> This stark contrast with the 2012 figure suggests more than just simple population growth. It reflects a deeper understanding of the caregiving role and the broadening of research methodologies to identify individuals who were previously unseen. The Elizabeth Dole Foundation's work in this area has been pivotal, not just in funding the research but also in establishing the "Hidden Heroes" campaign to raise public awareness.<sup>5</sup> The significant increase in the estimated caregiver population reveals that a large community was always present, but only now, through concerted advocacy and improved research, are they truly emerging from the shadows and being counted as an essential component of the national support structure for service members and veterans.

## 1.2 The Profile of the Modern Military Caregiver

The profile of a military caregiver differs in several key ways from a civilian caregiver. Demographically, caregivers in military families are younger than those in the general population, and a greater proportion are female and married.<sup>6</sup> A notable phenomenon among this group is "sandwiched" caregiving, where individuals are simultaneously responsible for multiple dependents. According to a Syracuse University study, 44 percent of military family

caregivers care for more than one person at a time, such as a child with special needs, a typically-developing child, and a parent or grandparent.<sup>6</sup> This creates a compounded burden of competing responsibilities that intensifies the complexity of their daily lives.

One of the most profound and challenging aspects of military caregiving is the issue of self-identification. More than a quarter (26 percent) of the caregivers surveyed reported feeling "excessively burdened" by their tasks but did not define themselves as "unpaid caregivers".<sup>6</sup> This lack of self-recognition is a critical barrier to help-seeking. When government and non-profit programs are labeled with terms like "Caregiver Support Program" or "Caregiver Network," they may fail to connect with the very individuals they are designed to serve. These individuals, who are already overwhelmed, may not search for these resources or see themselves as the intended audience. This dynamic suggests that a fundamental shift is needed in how support programs are presented, moving away from a generic identity and toward addressing the specific, day-to-day needs of parents, spouses, or children, thereby making the path to assistance more intuitive and accessible.

### **1.3 The Weight of the Invisible Wounds**

The nature of the conditions cared for in the military community is often a key differentiator. While civilian caregivers are more likely to care for older individuals with physical ailments, military family caregivers are most commonly caring for recipients with "invisible" conditions.<sup>6</sup> The most prevalent of these are emotional or mental health concerns, including traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD).<sup>6</sup>

This reality presents unique and demanding challenges. Caregivers must be prepared to address the cognitive, emotional, and physical impairments that accompany these conditions, such as memory loss, mood swings, paranoia, and difficulty processing information.<sup>7</sup> Unlike visible physical injuries, the psychological nature of these wounds can be difficult for outsiders to comprehend, leading to a profound sense of isolation and a constant need for the caregiver to justify or explain their struggles.<sup>8</sup> The experience of caring for a loved one who is physically present but psychologically altered can feel like a profound loss, a sentiment articulated in one caregiver's testimonial: "it feels like the man I married died over there, but yet I couldn't even grieve because his body, alive and breathing, was right in front of me".<sup>8</sup> This highlights the need for support that is not only practical but also deeply empathetic and validating.

## **Chapter 2: The Multifaceted Burdens of Service**

## **2.1 The Psychological and Physical Toll**

Caregiving for a military service member or veteran is a role that carries significant psychological and physical burdens. A greater proportion of military family caregivers experience mental health challenges and sleep issues compared to their non-caregiving peers.<sup>6</sup> The emotional toll is particularly severe among those caring for younger veterans, with a recent RAND report finding that 42 percent met the criteria for depression, and a harrowing 20 percent had considered suicide in the past year.<sup>3</sup>

The intensive time commitment and demanding nature of the work are central to this health crisis. Many caregivers spend 40 hours or more per week providing care, a workload equivalent to a full-time job.<sup>7</sup> The tasks can be physically demanding, requiring assistance with mobility, personal care, and activities of daily living.<sup>7</sup> This relentless cycle of high demand and emotional stress can lead directly to burnout and self-neglect. A powerful connection exists between the high demands of caregiving and the deterioration of the caregiver's own health. The evidence suggests that the physical and mental health of the caregiver is often a casualty of their dedication, as seen in the statistic that about half of those caring for a younger veteran had not seen a doctor in the past year.<sup>3</sup> This self-neglect, fueled by exhaustion and stress, is a clear contributing factor to the high rates of depression and suicide ideation within this community. The implication is that any effective support strategy must be holistic, prioritizing the caregiver's own well-being and resilience just as much as it prioritizes the needs of the veteran.

## **2.2 Navigating a Complex Labyrinth: Lifestyle and Financial Strain**

Beyond the direct burdens of care, military caregivers must also contend with the inherent complexities of the military lifestyle. Frequent relocations, separations from the service member, and isolation from established family and friends are common stressors that are intensely amplified for caregivers.<sup>6</sup> Each new location necessitates the challenging process of re-establishing a local support network and navigating a new set of community resources.<sup>6</sup>

Financially, the burden is equally significant. Caregivers report more financial stress than their non-caregiver peers, with out-of-pocket care costs averaging \$8,583 and an annual forgone income of \$4,500.<sup>3</sup> A third of military caregiving households have incomes below 130 percent

of the federal poverty level, yet a substantial number of these families are not utilizing the benefits to which they are entitled.<sup>1</sup> This is a critical and paradoxical finding. The problem is not a complete absence of resources but rather the existence of a labyrinthine system that prevents those most in need from accessing them. The overwhelming complexity of navigating the VA healthcare system, with its bureaucratic hurdles and confusing eligibility rules, adds another layer of stress to an already burdened population.<sup>7</sup> While numerous government and non-profit programs exist, the sheer volume and fragmented nature of the support landscape can be a significant deterrent, demonstrating a systemic failure to effectively connect resources with the individuals who urgently require them.

## Chapter 3: The Ecosystem of Support: A Guide to Resources

### 3.1 Governmental Support: The VA and DoD

#### 3.1.1 The VA Caregiver Support Program (CSP): Two Tiers of Assistance

The Department of Veterans Affairs (VA) is the primary governmental body offering support to caregivers through its Caregiver Support Program (CSP). This program is structured into two distinct tiers, each with different eligibility criteria and a different range of benefits.

The first tier is the **Program of Comprehensive Assistance for Family Caregivers (PCAFC)**. This program provides the most robust support and is for veterans who sustained or aggravated a serious injury or illness in the line of active-duty federal military service, and who require at least six months of continuous, in-person personal care.<sup>10</sup> For eligible primary caregivers, the benefits are substantial and include a monthly stipend, access to health care through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA), mental health counseling, and free legal and financial advice.<sup>10</sup> The application process for PCAFC requires the veteran and caregiver to apply jointly.<sup>10</sup>

The second tier is the **Program of General Caregiver Support Services (PGCSS)**. This program has a broader eligibility and is available to caregivers of veterans from any service

era who are enrolled in VA health care.<sup>11</sup> Unlike PCAFC, PGCSS does not provide a stipend or health insurance. Instead, it offers essential clinical services such as peer support mentoring, skills training, one-on-one coaching, and referrals to other community resources.<sup>12</sup>

The VA's caregiver programs have been subject to controversy and policy changes, particularly concerning a group known as "legacy" participants—those enrolled before October 1, 2020.<sup>14</sup> Concerns over new eligibility rules led to a pause on dismissals, which has been extended through September 2028.<sup>14</sup> This extension is a direct result of advocacy efforts from organizations like the Elizabeth Dole Foundation, which highlighted the need for stability for the nearly 15,000 families enrolled in the program.<sup>16</sup> This ongoing policy debate demonstrates the dynamic nature of government support and the vital role that non-profits play in advocating for the needs of the community.

Feature	Program of Comprehensive Assistance for Family Caregivers (PCAFC)	Program of General Caregiver Support Services (PGCSS)
<b>Eligibility</b>	Veterans with a serious service-connected injury who need continuous, in-person personal care for at least six months	Caregivers of Veterans enrolled in VA health care who served in any era
<b>Benefits</b>	Monthly stipend, CHAMPVA health care access, mental health counseling, travel benefits, legal and financial advice, respite care	Skills training, peer support, coaching, online programs, referrals to community resources
<b>Caregiver Relationship</b>	Spouse, parent, child, step-family member, extended family member, or someone living full-time with the Veteran	Can be a relative or non-relative; does not need to live with the Veteran
<b>Application Process</b>	Veteran and caregiver must apply together	Veteran must be enrolled in VA health care and agree to receive care from the caregiver

### 3.1.2 Support within the DoD: Military OneSource and Beyond

In addition to the VA, the Department of Defense (DoD) provides critical support, primarily for active-duty families. **Military OneSource** serves as a centralized hub, offering a range of services from confidential counseling and financial coaching to assistance with navigating complex systems like the military healthcare system or special needs planning.<sup>17</sup> The platform also hosts the Military Caregiver Personalized Experiences, Engagement and Resources (PEER) Forums, which provide opportunities for counseling and discussion on topics such as stress management and financial wellness.<sup>17</sup> The

**Air Force Wounded Warrior Program (AFW2)** serves as a service-specific model for care, offering support through wellness checks, resiliency training, and education on topics like PTSD and TBI.<sup>18</sup> These programs are crucial for providing immediate and accessible support within the active-duty community, and they serve to bridge the gap between service-connected care and the full transition to veteran status.

## 3.2 Non-Profit and Private Sector Partnerships

The non-profit sector plays a vital and complementary role, often providing the community-focused support that governmental programs may not.

### 3.2.1 Peer Support and Community Building

The non-profit sector excels at fostering a sense of community and shared understanding. The **Elizabeth Dole Foundation's "Hidden Heroes" Campaign** is the flagship public awareness campaign that brings attention to the untold stories of military caregivers and seeks solutions for the long-term challenges they face.<sup>5</sup> Their "Hidden Heroes Caregiver Community" is an online support group that connects caregivers of all eras, allowing them to share stories, seek advice, and find commonality in their experiences.<sup>5</sup> Similarly, the

**American Red Cross's Military and Veteran Caregiver Network (MVCN)** provides a secure, customized online platform for peer support, as well as one-on-one and group mentoring led by trained caregiver facilitators.<sup>19</sup> These networks are critical in combating the

feelings of isolation that are common among caregivers.<sup>19</sup>

**Blue Star Families** offers its own **Blue Star Caregivers Program**, which focuses on peer-to-peer connections and self-care.<sup>21</sup> The program's "Support Circles" are non-clinical, facilitated cohorts designed to empower family members to recognize and intervene safely when a service member or veteran is heading toward a crisis.<sup>21</sup> This upstream approach to suicide prevention, funded by a VA grant, highlights the strategic role non-profits play in identifying and addressing emergent needs.

### 3.2.2 Targeted Assistance: Financial, Legal, and Respite Care

Many non-profits provide direct, targeted assistance to fill specific gaps. The **Bob & Dolores Hope Foundation Fund** for Critical Financial Assistance is a prime example, offering financial relief grants to military and veteran caregivers for needs such as utilities, housing, and medical bills.<sup>22</sup> The application process is ongoing, with funds disbursed directly to the vendor (e.g., landlord or utility company) to ensure they are used for their intended purpose.<sup>22</sup>

**Respite care** is another crucial service, providing a temporary break from the relentless demands of caregiving. The VA offers three forms of formal respite care through its Office of Geriatrics and Extended Care: in-home care from an agency employee, adult day health programs, and temporary nursing home stays.<sup>23</sup> In addition to these formal options, the VA encourages and provides tools for caregivers to practice self-guided respite (e.g., meditation or journaling) and informal respite (e.g., help from friends or family).<sup>24</sup>

### 3.3 Mental Health and Crisis Support

The mental and emotional health of both the caregiver and the care recipient is a central concern. The **988 Suicide & Crisis Lifeline** offers 24/7 access to trained crisis counselors for anyone experiencing mental health distress, and it has a dedicated option for veterans and their families by pressing "1".<sup>21</sup> This resource provides a critical safety net for a community with disproportionately high rates of depression and suicide ideation.<sup>3</sup>

The non-profit sector provides further specialized support. The **Cohen Veterans Network** offers accessible, high-quality mental health care for veterans and their families.<sup>21</sup> Programs like the VA's

**Building Better Caregivers (BBC)**, a free online program for caregivers of veterans with dementia or TBI, provide skills and a sense of community, helping individuals feel less alone in their journey.<sup>20</sup> This multi-faceted approach, combining a national crisis hotline with specialized clinical and peer-based programs, underscores the recognition that mental health is a foundational component of caregiving support.

## **Chapter 4: Lived Experiences: Voices from the Caregiving Journey**

Statistics and policy breakdowns provide the structure for understanding military caregiving, but personal narratives provide the heart. An anonymous caregiver's account of caring for her husband with invisible wounds, including TBI and PTSD, illustrates the emotional and psychological realities of the experience.<sup>8</sup> She recounts the pain of watching the "new guy" replace the man she married, a powerful metaphor for the grief that caregivers experience while their loved one is still alive. Her story also highlights the profound sense of validation she felt when a VA nurse finally saw their struggles without judgment or skepticism, stating, "I felt so validated, finally, people believe me".<sup>8</sup> This validates the importance of having programs and professionals who are trained to understand the unique manifestations of military-related conditions.

The testimony of Vicki, a caregiver who used the VA's Building Better Caregivers program, further demonstrates the transformative power of community.<sup>20</sup> After years of feeling stressed and isolated, she found a lifeline in a program that connected her with other caregivers. Her relief was palpable, as she shared, "You cannot imagine how encouraging it is to think, 'You, too?!'".<sup>20</sup> This simple phrase perfectly captures the essence of peer support and the reduction of isolation that is a primary goal of many non-profit initiatives. These stories prove that the most effective resources are those that address the emotional and social needs as much as the practical ones, providing not only a stipend or a service but also a sense of belonging and understanding.

## **Conclusion: A Call to Continued Action and Recognition**

Caregiving in the military community is a multifaceted and complex national issue. While a

robust ecosystem of support exists, it is not without its challenges. The journey of these 14.3 million caregivers is marked by unique burdens—from the psychological demands of "invisible wounds" to the logistical and financial strain of the military lifestyle.

The analysis presented in this report reveals a crucial duality: while governmental programs, particularly those from the VA, provide essential financial and medical benefits, the non-profit sector is invaluable for its focus on peer-to-peer support, community building, and addressing the nuanced emotional and social needs of caregivers. The current policy discussions surrounding the PCAFC program and the ongoing advocacy for "legacy" participants underscore that this is a dynamic landscape, requiring continuous attention and adaptation. The existence of a vast but underutilized network of benefits points to a fundamental need for improved awareness and streamlined access. The path forward must involve ongoing research to bring more of these "Hidden Heroes" into the light, coupled with a concerted effort to connect them to the resources and communities that stand ready to support them. It is through this sustained commitment that the nation can truly honor those who care for our wounded warriors.

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