

VA Caregiver Support Program

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Why Family Caregivers Matter

- National Alliance for Caregiving and Evercare Survey indicates that the value of services family caregivers provide "for free" when caring for older adults is estimated at \$375 billion (nation-wide).
- Without family care, many people could not live in the community.
- Caregivers spend about 20.4 hours per week providing care.
- Caregivers of Veterans are in their role for a longer period (10 years or more), and their burden of care is also heavier—65% are in a high burden caregiving situation compared to 31% nationally.
- Caregivers make significant contributions to the successful outcomes of Veterans' healthcare.

The RAND Military Caregivers Study

- Significant attention has been paid to Service Members and Veterans with servicerelated injuries and associated conditions, but little is known about the needs of their caregivers or the resources that exist to meet them.
- RAND Corporation Study, "Hidden Heroes: America's Military Caregivers", 2014.
- Focuses on the caregivers of wounded, ill, and injured military Service Members and Veterans.
- The study aims to describe the magnitude of military caregiving in the U.S. today, as well as to identify gaps in the array of programs, policies, and initiatives designed to support military caregivers.
- http://www.rand.org/military-caregivers.

Caregiver Statistics

9% of U.S. adults are caregivers

16.9 million civilian caregivers

4.4 million Pre-9/11 military caregivers

1.1 million Post-9/11 military caregivers

Source: National survey of caregivers of adults in the U.S., with findings presented in Ramchand R, Tanielian T, et al., Hidden Heroes: America's Military Caregivers, RAND Corporation, 2014 (available at www.rand.org/military-caregivers). © RAND 2014

Military Caregivers

- Many wounded, injured, or disabled Veterans rely for their day to day care on informal caregivers: spouses, parents, children, friends, or other family members who devote substantial amounts of time and effort to caring for them.
- These informal caregivers, *military caregivers*, play a vital role in facilitating the recovery, rehabilitation, and reintegration of wounded, ill, and injured Veterans.
- They are our country's hidden heroes: Their support keeps Veterans out of institutions and helps them live longer, higher-quality lives.
- In the most comprehensive study ever done on military caregivers, it was found they fell into two distinct groups: Those caring for Veterans who served in the military before September 11, 2001, and those caring for Veterans who served after September 11, 2001.
- These two groups of caregivers differ in fundamental ways with respect to the burdens of care, and the kinds of support they need.

Hidden Heroes: America's Military Caregivers, RAND Corporation, 2014 (available at www.rand.org/military-caregivers). © RAND 2014

Pre 9/11 Caregivers

- Caring for Veterans from the pre-9/11 era—In many respects, these caregivers resemble those whom we call *civilian caregivers* (those who care for non-Veterans).
- Pre-9/11 Veterans receiving informal care generally fit the traditional profile of an elderly person whose needs are related to aging. A relatively small percentage of these care recipients 30 percent have disabilities specifically related to their military service. The most common problems reported by these individuals are chronic diseases (such as hypertension, cancer, or diabetes) or cognitive impairments, such as dementia. About three-fourths also report physical problems.
- Most of the caregiving support provided to these pre-9/11 Veterans involves assistance with
 the functional tasks of daily living often associated with elderly care, such as bathing,
 dressing, managing medications, or preparing meals. In providing this care, the large majority
 of pre-9/11 caregivers 71 percent can draw on a network of additional family and
 friends for support.

Post 9/11 caregivers

- In contrast, post-9/11 military caregivers present a very different profile. Most commonly, the caregiver is a young spouse or a parent taking care of a child, although a surprisingly large number of these caregivers are friends or neighbors.
- In many cases, post-9/11 caregivers are juggling multiple responsibilities. Nearly two-thirds are employed, and 40 percent are raising at least one child.
- The Veterans whom this group cares for also differ. Most are young, and they are more likely than older Veterans to suffer from the invisible wounds associated with combat experience. Nearly two-thirds have mental health or substance use disorders (including posttraumatic stress disorder, depression, and anxiety), and one-fifth have traumatic brain injuries; these impairments are roughly twice as prevalent as they are among pre-9/11 care recipients.
- Because of this group's unique care needs, post-9/11 military caregivers typically spend less time with the traditional tasks of elderly caregiving (such as helping with bathing and dressing) but spend more time helping their loved one cope with stressful situations or behavioral challenges or avoid triggers of anxiety and PTSD. And, unlike pre-9/11 caregivers, a majority lack a caregiving network that could support them.

Hidden Heroes: America's Military Caregivers, RAND Corporation, 2014 (available at www.rand.org/military-caregivers). © RAND 2014

Post 9/11 Caregivers

- Because of the lack of support network, post 9/11 caregivers are more likely to use mental health resources and services, and to use them more often.
- Post 9/11 caregivers report experiencing poor health outcomes, greater strains in family relationships, and more workplace problems.
- Nearly 1/3 of post 9/11 military caregivers lack health care coverage.
- Post-9/11 caregiver duties can be estimated as worth close to \$3 billion (in 2011 dollars); Post 9/11 military caregivers report missing 3.5 days of work per month on average. The costs of lost productivity among post-9/11 caregivers are \$5.9 billion (in 2011 dollars).

Caregiving comes at a cost

- The costs of caregiving are not just financial. The toll of providing care can be high.
- Caregivers themselves may feel overwhelmed or unprepared for the duties they are expected to perform.
- It has been found that time spent caregiving can lead to the loss of income, jobs, or health care and exact a substantial physical and emotional toll.
- Caregiving responsibilities may also alter in both positive and negative ways –
 the dynamics within their families, including marital quality and the ability to care
 for their children.

Caregiving comes at a cost

- Caregivers in general face elevated risks for depression. About 20 percent of both civilian caregivers and pre-9/11 military caregivers are at risk for major depression, which is roughly double the rate for non-caregiving adults.
- But post-9/11 caregivers are four times more likely than non-caregivers to be at risk for major depression. Two defining features of post-9/11 caregiver activities the added time spent caregiving and the help given to loved ones coping with stress and behavioral problems contribute directly to depression.
- The impacts of caregiving on families are also worse for post-9/11 military caregivers. Those who are caring for spouses report lower-quality marital relationships, which, combined with their young age, is likely to increase the risk of future divorce. This, in turn, will increase the need for "substitute" caregivers in the future.

Hidden Heroes: America's Military Caregivers, RAND Corporation, 2014 (available at www.rand.org/military-caregivers). © RAND 2014

VA recognizes the importance of Caregivers

- Honoring America's Veterans by ensuring their well-being remains a national priority. Military caregivers play a central role in helping to do this, but caregivers cannot go it alone.
- To the extent that their own well-being is compromised, caregivers could become unable to care for their loved one, leaving the responsibilities to be borne by other members of society.
- Thus, ensuring the well-being of military caregivers is paramount to fulfilling the national promise to Veterans.

Caregivers and Veterans Omnibus Health Services Act of 2010, Public Law 111-163

- In May 2010, President Barack Obama signed into law the Caregivers and Veterans Omnibus Health Services Act of 2010, Public Law 111-163.
- Title I of the law established 38 U.S.C. 1720G, which requires VA to "establish a program of comprehensive assistance for family caregivers of eligible Veterans," as well as a program of "general caregiver support services" for caregivers of "Veterans who are enrolled in the health care system".

Goals of P.L. 111-163

- To provide care to a qualified family member that connects to the treatment plan of the Veteran, so that services provided to the family member will be a component of VA's overall treatment of the Veteran's disability.
- To benefit eligible Veterans whose personal care service needs could be substantially satisfied with the provision of such services by a family member; and to provide eligible Veterans with additional options so they can choose the setting for the receipt of personal care services that best suits their needs.

P.L. 111-163

The law authorizes increased assistance for caregivers of Post 9/11 Veterans and Service Members. It recognizes that Post 9/11 Veterans and Service Members return home with serious injuries that often were fatal in the past. These Veterans present complex recovery and adjustment processes requiring ongoing medical supervision.

P.L. 111-163 Section 101 Veteran Eligibility Criteria:

Veteran who suffered a serious injury incurred or aggravated in the line of duty on or after 9/11/01, including traumatic brain injury and psychological trauma or other mental disorder

<u>and</u>

Is in need of personal care services because of

- an inability to perform <u>one</u> or more activities of daily living;
- a need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury.

General Caregiver Program Benefits

Available to Caregivers of Veterans of All Eras:

- Education and Training
- Family Support Services
- In-Home Care
- 30 Days of Respite Care per year
- Aid and Attendance (financial benefit)
 - Veterans and survivors who are eligible for a VA pension and require the aid and attendance of another person, or are housebound, may be eligible for additional monetary payment.
 - Any War-Time Veteran with 90 days of active duty is eligible to apply for the Aid & Attendance Improved Pension. A surviving spouse (marriage must have ended due to death of Veteran) of a War-Time Veteran may also apply. If you are a Veteran with a 30% or greater combined VA service-connected disability rating, and your spouse needs the aid and attendance of another person, you may be entitled to get a spouse-related A&A payment.
 - Veteran and Caregivers should contact their local Veteran County Service Officer for further assistance with the Aid & Attendance benefit.

General Caregiver Program Benefits

- Caregiver Support
 - Support Groups
 - Caregiver Support Coordinators
 - Interactive VA Caregiver Website
 - Peer Mentoring Program
 - Building Better Caregivers
 - National Caregiver Support Line
 - Caregiver Self Care Courses

Program of Comprehensive Assistance Additional Benefits under P.L. 111-163 *Available to eligible post 9/11 Veterans

- Monthly stipend paid to Family Caregiver
 - Based on wages of a home health aide in the geographic area where the Veteran resides
 - Tiered based on amount and degree of personal care services provided
 - Many caregivers have left employment due to the time commitment required to provide care for a seriously injured Veteran.
- CHAMPVA Health care coverage
- Mental health services
- Comprehensive instruction and training
 - to ensure Caregiver is able to provide care in a manner that protects the safety and well being of the Veteran
- Well-being checks every 90 days:
 - Home visits are supportive and instructive.
 - Evaluation of Veteran and caregiver's physical and emotional state.
 - Recommendations for additional training, support, equipment, etc.
- Travel, lodging, and per diem for training
- Enhanced respite care
 - Medically appropriate with options for 24/7 in-home care
 - Hero Miles
- Lodging and subsistence for Veteran's appointments at VA.

Building Better Caregivers

- An interactive, web-based workshop developed by Stanford University and launched by VA Caregiver Support Program in Fall 2012.
- Workshop is designed to provide education, support and teach problem solving to Caregivers of Veterans of all eras.
- Trained moderators facilitate the program and courses.
- Six-week workshop topics include stress management, difficult behaviors, sleep, healthy eating, exercise, difficult emotions for both the care recipient and Caregiver, decision making, resources, and planning for the future.

Fisher House Foundation Hero Miles Program (Post 9/11)

- Fisher House Foundation's Hero Miles program provides assistance with airline travel for family members or friends traveling to a Veteran's home to provide respite care.
- The goal of respite care is to provide Family Caregivers temporary relief from the demands of the daily care they provide seriously injured Veterans.
- This respite program is more appealing to post 9/11 Veterans that generally aren't as comfortable with traditional respite care provided through community agencies.

Peer Support Mentoring Program

- Developed to strengthen relationships between caregivers, to provide an opportunity for networking and to empower caregivers to help one another.
- 1:1 support.
- Peer mentors provide personal support to their mentees, assist with navigation of daily stressors, and serve as role models for individuals who need help.
- Because there are many challenges to being a Caregiver, it can be helpful for a caregiver to talk to someone who has "been there" and understands the pressures that come with being a caregiver.
- Benefits of having a peer mentor:
 - Creating an outlet for socializing and networking.
 - Learning from the experience and support of those who understand the challenges caregivers face.



Caregiver Support Coordinators

- Clinical experts on caregiver issues including VA and non-VA resources. Provide access to resources.
- Assist caregivers with navigating the VA system.
- Provide emotional support to caregivers.
- Conduct assessments on caregiver's physical, mental, spiritual, emotional and social needs, including assessing for caregiver burden and burnout.
- Organize caregiver-focused activities and services (i.e., National Family Caregiver Month) to promote social support.
- Respond to VA Caregiver Support Line referrals.
- Ensure caregiver sensitivity is integrated into all programs.
- Provide education on tools for coping, stress management techniques, self care, and effective communication skills.

VA Caregiver Support Program Mission Statement

VA Caregiver Support Program Mission Statement:

 "to promote the health and well-being of family Caregivers who care for our nation's Veterans, through education, resources, support, and services."

• Despite the high level of stress that Caregivers of Veterans may endure, 94% reported that they are "proud to serve" (National Alliance for Caregiving and United Health Foundation, 2010, "Caregivers of Veterans – Serving on the Homefront").

Remember

There are only 4 kinds of people in the world:

Those who have been caregivers,
Those who are currently caregivers,
Those who will be caregivers,
And those that will need caregivers.

~ Rosalyn Carter

Questions?

