



## *The Technical Assistance Center for Lifespan Respite Fact Sheet Number 63, August 2015*

### **Respite for Caregivers of Veterans**

#### **Introduction**

Respite for caregivers of Veterans from all eras is a recognized, but often unmet need. Special considerations for the development and implementation of respite care for caregivers of younger Veterans with disabilities, and new ways to improve access to services, may be required.

Veterans have unique physical, emotional and behavioral conditions that require care beyond that of the general population. As the number of aging Veterans grows, so does the number diagnosed with dementia including Alzheimer's. Younger Veterans who have traumatic brain injury (TBI), spinal cord injuries, amputations and posttraumatic stress disorder (PTSD) compose a special subgroup of Veterans whose respite care needs may include the provision of medically-complex treatment and/or mental health services.

It is estimated that 80% of Veterans who access health care through the US Department of Veterans Affairs (VA) also access health care in the community, requiring care coordination between systems that do not formally communicate with one another. Individuals caring for Veterans, similar to all caregivers, often need a break from their caregiving responsibilities. Respite care, in its many forms, can provide rejuvenating time away from daily caregiving responsibilities and a much-needed break for the Veteran as well.

However, respite is not always a service caregivers of Veterans are aware of or use, especially those caring for Veterans with serious impairments. The availability of respite care for caregivers of Veterans

often depends on where the Veteran lives and the nature of the Veteran's disability or condition, especially neurological or mental health conditions. Appropriate and desired respite services specifically targeted for this population are extremely limited and the need is growing.

This fact sheet provides a basic review of respite issues for providers who work with Veterans and their caregivers. It will also help Lifespan Respite grantees better understand the unique needs of Veterans. Such insights will help State Lifespan Respite programs and others be better positioned to create strategies that address these needs and thereby increase access, quality of services and provider training to serve this population. Family caregivers may also find useful resources here.

#### **Veteran Population**

Veterans are men and women who have concluded a period of service in the armed forces; U.S. Army, Navy, Air Force, Marine Corps, or Coast Guard. Persons who served in the U.S. Merchant Marine during World War II and those who were ordered to active duty while in the National Guard or Reserves are also classified as Veterans. Veterans who served in Operation Enduring Freedom (Afghanistan), Operation Iraqi Freedom (Iraq), or Operation New Dawn (Iraq) are sometimes referred to as post-9/11 Veterans, meaning they served in the military after September 11, 2001.

The number of Veterans overall in the US has been declining in recent years, while the numbers of Veterans with service-connected disabilities has

been climbing. In 2014, there were approximately 22 million Veterans, a decline of 26 percent since 1986. Nearly 4 million Veterans currently have a service related injury, a 60 percent increase since 1990 (National Center for Veterans Analysis and Statistics [NCVAS], 2015). Close to 10 million Veterans are over the age of 65 (NCVAS, 2014).

When compared to Veterans of previous wars, recent Veterans sustained different types of injuries. Due to body armor and improved battlefield care, many are surviving wounds and injuries that previously would have been fatal. Moreover, the ability of the medical community and the VA to diagnose and treat PTSD continues to improve (Bahraini & Brenner, 2014).

Depression and anxiety, PTSD, and spinal cord injuries are more common among younger Veterans, particularly those who served in Vietnam or later. The proportion of caregivers of Veterans who sustained a TBI jumps among those caring for the youngest Veterans who served in recent wars (Ramchand, et al., 2014).

In contrast, pre-9/11 Veterans with disabilities have significantly higher rates of mental health issues, substance abuse, hearing and vision problems, and chronic, physical impairment when compared to the general population. Additionally, Veterans, who served in the Vietnam War or earlier, have a higher incidence of diabetes or cancer than the general population in their same age group (Ramchand, et al., 2014).

Veterans are at increased risk of developing Alzheimer’s disease or a related dementia if they suffer from PTSD or TBI. In fact, TBI in older Veterans is associated with a 60 percent increase in the risk of developing dementia (Barnes, et al., 2014). Similarly, the prevalence of dementia is greater in Veterans with PTSD, although further research is needed to confirm a causal relationship (Qureshi, et al., 2010). Research has suggested that

the prevalence of dementia in Veterans will rise dramatically due to the increasing incidence of PTSD and TBI (Sibener, et al., 2014).

## Family Caregivers of Veterans

With sponsorship from the Elizabeth Dole Foundation, the Rand Corporation conducted comprehensive research on caregivers of veterans and published the report, *Hidden Heroes: America’s Military Caregivers*. According to the report, there are 5.5 million caregivers of Veterans and service members. The majority of caregivers support older Veterans who served in wars prior to 9/11. Twenty percent, or 1.1 million, care for service members who served post 9/11 (Ramchand, et al., 2014).

Caregivers of pre-9/11 Veterans look more like caregivers in the general population. However, post-9/11 caregivers are very different in terms of their demographics and caregiving burden. Caregivers of post-9/11 Veterans have less access to support and, when compared to other caregivers of Veterans, are more likely to be a friend or spouse, ages 18 to 30, or an aging parent (Ramchand, et al, 2014).

### Differences between Pre-9/11 and Post-9/11 Military Caregivers

	Pre-9/11 Military Caregivers	Post-9/11 Military Caregivers
Relationship to care receiver	Child	Spouse
Employed outside the home	47%	63%
Support network available	71%	47%
Care receiver has behavior problems	36%	64%
VA disabled status	30%	58%

Source: Rand Corporation (2014). *Brief: Military Caregivers – Who are they? And who is supporting them?*

### Unique Stressors Affect the Health and Wellbeing of Caregivers of Veterans

Being injured in the line of duty can be frightening for service members and their families. In an instant, everything is altered, creating tumultuous emotions and changes in daily activities and future plans.

Spouses may feel abandoned and overwhelmed; other family and friends may feel helpless; and the injured Veteran may be sad, confused and angry. Those who provide day to day assistance face tremendous challenges in this new role of caregiver.

Several research studies have confirmed that nearly all caregivers of Veterans experience impacts on their health and wellbeing. One study found 68 percent of caregivers report their situation as highly stressful compared to 31 percent of caregivers nationally. Caregivers of Veterans experience a high degree of physical strain (40%) compared to caregivers in the general population (14%). Stress and anxiety are reported by 88 percent of caregivers of Veterans and sleep deprivation by 77 percent. Likewise, these caregivers report spending less time exercising (69%) and skipping their own medical visits (58%). Fifty-six percent report poor eating habits. Six in ten also experience body pain due to the physical demands of caregiving (National Alliance for Caregiving [NAC], 2010).

Specific subsets of caregivers experience even greater pressure. Caregivers of Veterans with behavior problems, TBI and PTSD report higher rates of depression (Ramchand, et al., 2014; NAC, 2010). About half of caregivers of a Veteran with TBI report that caregiving is very difficult and experience negative health effects. Caring for a paralyzed Veteran is very demanding; these caregivers are almost twice as likely as other caregivers to provide assistance more than 80 hours per week. A significant percentage of these caregivers consider their situation as a high burden (80%) and report stress often (73%). In addition, caregivers of Veterans living in rural communities and small towns were also more likely to be depressed than those caregivers living in urban and suburban communities (NAC, 2010).

### ***Caregiving Affects Relationships***

Post-9/11 military spousal caregivers report the lowest relationship quality compared with caregivers of other generations of service members. There is a greater risk of separation or divorce for younger Veterans. Moreover, providing care for

those with neurological or other serious medical conditions can increase stress for the entire family. When a Veteran is suddenly faced with the loss of abilities due to conditions like TBI or spinal cord injury, depression is common for the entire family, relationships are redefined and simple everyday tasks become challenging (Ramchand, et al., 2014). The Veteran may need intensive support, sometimes 24 hours a day, taking away from normal family time. Research by the National Center on PTSD at the VA documents a negative impact of PTSD on families. Marital problems, family violence, and distress and behavior problems in children are more frequent outcomes in families with Veterans who have PTSD (Price & Stevens, nd).

### ***Financial Effects of Caregiving***

According to the Rand study, military caregivers bear economic challenges through the cost associated with providing care (e.g., health care costs, program costs) and through lost income and wages when the Veteran can no longer work or faces difficulty finding employment. In addition, the caregiver frequently must relinquish or reduce employment to provide care. The financial impact disproportionately affects post-9/11 caregivers. Approximately twice as many post-9/11 military caregivers (47%) reported needing to make work adjustments as a result of caregiving as pre-9/11 caregivers (23%) and civilian caregivers (27%). As a result, almost two-thirds of post-9/11 military caregivers (62%) reported that caregiving caused financial strain compared to pre-9-11 caregivers (30%) and civilian caregivers (38%) (Ramchand, et al., 2014).

### ***Respite Challenges for Caregivers of Veterans***

Veterans can use any respite service available in the community if they meet the eligibility criteria. However, there may be limited programs or services for which they qualify and then their specific needs may not be adequately addressed. This is particularly true for many post-9/11 Veterans. A 2014 environmental scan of programs nationwide

supporting military caregivers conducted by the Rand Corporation identified only nine respite programs that would be appropriate for military families. This number represented only 7% of the 127 military caregiver support programs identified by the scan (Ramchand, et al., 2014). Moreover, if caregivers do not feel respite providers are trained to handle their loved one or do not consider the special circumstances faced by military families, they will be more hesitant to use respite services. These caregivers are less likely to know where to go to access these resources. Here are a few specific challenges caregivers of Veterans may face.

### ***Eligibility and Financial Barriers***

Eligibility for most VA support programs in our country is determined by the status of the Veteran rather than family members or friends who are their caregivers. The VA's *Program of Comprehensive Assistance for Family Caregivers* targets family caregivers as the direct recipient of services and supports, but the Veteran must meet certain eligibility criteria for their caregivers to qualify. (See federal programs on page 8). In addition, many state and federal caregiver programs, including Medicaid home and community-based waivers, are designed for caregivers of older adults or limited to specific disabilities or conditions, such as autism or intellectual and developmental disabilities. Consequently, caregivers of post-9/11 Veterans may not be eligible for services available outside of the VA as they could be disqualified due to age or condition. This is especially problematic given the severe financial strain that Veterans and their caregivers face compared to other caregivers, as described in the previous section, leaving them little disposable income available to pay for respite.

### ***Lack of Knowledge about Respite Leads to Limited Use***

In 2010, only 15 percent of family caregivers of Veterans had received respite services from the VA or some other community organizations within the past 12 months (NAC, 2010). In 2014, the percentage of caregivers of post-9/11 Veterans using

respite was only 20 percent (Rand Corporation, 2014). It is still not clear why these numbers are so low. However, often post-9/11 caregivers report not knowing about the few services that do exist. In fact, 75 percent of caregivers of Veterans with TBI do not know where to turn to arrange a break from caregiving (NAC, 2010).

Caregivers of older Veterans, 65 and older, are almost twice as likely to have used respite services as those providing care to a younger Veteran (20% vs. 12%). Persons caring for Veterans who have PTSD are half as likely as other caregivers to have received respite services (11% vs. 20%). The fact that respite utilization rates increase when care managers are assigned to caregivers supports the notion that caregivers do not know about respite and that caregivers specifically ask for respite resource lists and help accessing services (NAC, 2010).

Veterans may be resistant to participating in respite opportunities that are unfamiliar to them, are not age appropriate, or take them outside of their comfort zone. Providing appealing and desirable respite options may increase their willingness to participate. Educating them about the importance of respite for their family caregivers may be very important as well.

### ***Shortage of Trained Providers***

The shortage of long-term care workers in our nation has been well documented. Projections reported by the US Department of Labor estimate that over 1.3 million new paid caregivers will be needed to meet demand over the next decade. Couple this with limited or inadequate training of providers, especially for those who provide care for individuals with complex medical needs or serious mental health conditions. Currently, persons caring for Veterans with PTSD, depression and anxiety or TBI have greater difficulty finding someone to give them time off than those caring for other Veterans. It may be much more difficult in the future as the number of Veterans with disabilities climbs, especially those with PTSD or dementia, and the pool of available and well trained providers shrinks.

Many community-based providers also have a limited understanding of military culture, which can also be a barrier to acceptable respite services. The VA and the Department of Defense (DoD) developed *Military Culture: Core Competencies for Health Care Professionals*, a free online continuing education course to help health care professionals and others understand Veterans and their military experience. For more information, see <http://www.va.gov/HEALTH/NewsFeatures/2015/July/Helping-Your-Provider-Understand-Military-Culture.asp#sthash.1Kk7mzkH.dpuf>.

### **Limited Community-Based Respite Options**

While home and community based respite options are often preferred by Veteran family caregivers and by Veterans themselves, and such options may be permissible under many VA respite programs, the availability of such services can be limited. Community-based respite options that meet the social and/or medical needs of the younger Veteran, are sensitive to the special needs of military families, or are available for overnight or extended stays, are in especially short supply.

### **Considerations for Respite Referral**

The majority (46%) of military caregivers indicated that, in the past year, they used informal sources of information to find help to meet caregiving challenges, while only 11 percent reported using a referral service. These proportions did not significantly differ between pre-9/11, post-9/11, and civilian caregivers (Ramchand, et al, 2014). However, a well-established and useful point of entry for finding information about respite could prove essential given the barriers Veteran family caregivers face due to limited knowledge about respite and about how and where to access services.

The VA Caregiver Support Coordinators, who help implement the VA's Program of Comprehensive Assistance for Family Caregivers, are located in each VA Medical Center. They match caregivers with eligible services and provide information about

caregiver resources. According to the Rand study, the National Resource Directory and DoD Office of Warrior Care Policy, which publishes online and print versions of "Family and Caregiver Support" resources, may be helpful as well. Rand also identified military referral hotlines such as Military OneSource and DSTRESS as additional possible referral sources for military caregivers.

When looking for additional respite resources for Veterans outside of military or Veteran specific services, Veterans and their caregivers may want to look to a state's No Wrong Door System if they have one. In 2014, the Administration for Community Living (ACL), Centers for Medicare and Medicaid Services (CMS), and Veterans Health Administration (VHA) provided funding to 25 states and territories to assist them in the planning of a No Wrong Door (NWD) System that will make it easier for all populations in need of LTSS to learn about and access the services and supports they need. To date, 54 states and territories have been funded to implement NWD activities. Nationwide 530 local NWD systems are in place actively serving older adults and persons with disabilities.

State Lifespan Respite Programs or State Respite Coalitions also may be helpful to Veterans and their caregivers seeking respite services or providers. Linking these resources to each other as well as to caregivers directly is a worthy goal that would go a long way to improving not only access, but expansion of appropriate home and community-based respite services and more appropriately trained in-home and out-of-home respite providers.

See Veteran and Military Respite and Caregiver Resources on page 13 to find contact information for the referral options suggested here.

## Respite Options in the Community

The following in-home and out-of-home respite options may provide benefits for family caregivers of Veterans depending on individual caregiver and Veteran needs:

- **In-home respite** can be provided by nursing, homemaker or home health care agencies and volunteer organizations, who send workers into the home of the Veteran. The advantage of in-home respite is that the Veteran stays in a familiar environment and avoids transportation difficulties. Disadvantages of in-home care may include cost, limited socialization for the Veteran and concerns about the background of the workers. Added vigilance is required to ensure that the care is reliable and consistent over time.
- **Out-of-home respite** in community-based or volunteer and faith-based agencies may offer services that are more affordable for family caregivers and be more acceptable to younger Veterans, especially if activities of interest to the Veterans are offered and services are provided primarily for same-age peers. With adequate training, well supervised workers and volunteers can provide respite options for individuals who may not need as structured an environment as provided by adult day care services or nursing home respite options.
- **Voucher respite or participant-directed respite** allows the Veteran and the family caregiver to select and train a respite worker of their choice. They receive a voucher from a funding source and then the family and the Veteran control when, how and where respite is provided as well as how much to pay. Many Veterans and caregivers appreciate having some control over services, because they can personally screen for a worker who they view as compassionate and understanding of the Veteran's specific needs. It allows them to make arrangements that best fit their family's needs which might mean scheduling respite during non-traditional hours. On the other hand, this type of respite means Veterans and caregivers take full responsibility for the management of the worker

or volunteer. Caregivers and Veterans will want to decide in advance if they can handle the added responsibility of screening applicants, interviewing and possibly dismissing workers before considering this option.

- **Adult day care services** are hosted in a center during the day and typically provide supervised care and support. Some centers are medical models and deliver nursing, cognitive stimulation and other therapeutic services. Center operators may arrange transportation services as a convenience for the caregivers. Adult day care helps working caregivers feel secure that their relative is cared for during working hours. Keep in mind, however, that while most adult care services are available to provide care during regular daytime work hours to allow family caregivers to be employed full-time, public respite funding streams will rarely pay for adult day care used on more than a part-time or temporary basis. Also, as adult day services primarily serve the aging population, this option may not be the most desirable or appropriate setting for a younger Veteran.
- **VA Adult Day Health Centers**, run by the Veterans Health Administration, will assess a Veteran's rehabilitation needs and work toward maintaining or regaining personal independence. As with other respite services funded by the VA, services are available up to 30 days per year. For more information on VA ADHC: [http://www.caregiver.va.gov/support/support\\_services.asp#sthash.5BhD7hSc.dpuf](http://www.caregiver.va.gov/support/support_services.asp#sthash.5BhD7hSc.dpuf)
- **Respite in Long-term care facilities or hospitals** – Eligible Veterans can receive respite in VA Medical Centers, VA Community Living Centers, or a VA-contracted Community Residential Care Facility. Some nursing homes, hospitals, or assisted living facilities serving the non-Veteran population may also set aside a number of beds for short-term respite. Respite may be offered overnight, on weekends or for extended stays in these long-term care facilities. These services support caregivers who need a break for a full day or up to a couple of weeks. Caregivers

may choose to take a vacation, have medical procedures performed or simply rest during their respite time. This form of respite may offer the caregiver of someone with serious medical conditions additional comfort because nursing staff is available. Again, however, this may not be the most desirable setting for younger Veterans given limited activities and opportunities for socialization.

For examples of respite services or programs serving family caregivers of individuals with dementia, including Alzheimer's disease, neurological conditions, mental health conditions, or other special needs, see ARCH facts sheets on respite for specific populations at <http://archrespice.org/productspublications/arch-fact-sheets>.

## Unique Respite Options for Caregivers of Veterans

Caregivers of Veterans, especially of younger Veterans, may have unique respite needs that could require an understanding of military families' special needs, circumstances due to the Veteran's posttraumatic stress or other mental health needs, and military culture. The Yellow Ribbon Fund (below), the Wounded Warriors Family Support (page 8) and Legacy Corps Respite (page 9) are examples of respite provided by organizations with expertise in and understanding of the military experience.

### Yellow Ribbon Fund Caregiver Retreats and Other Supports

[www.yellowribbonfund.org](http://www.yellowribbonfund.org)

Winner of the Newman's Own Award, the Yellow Ribbon Fund (YRF) in Bethesda, MD, brings respite to caregivers of severely injured service members who are recuperating at Walter Reed National Medical Center. Founded to serve injured post-9/11 soldiers and Veterans, YRF provides free hotel rooms and apartments for visiting family members, free rental cars, and free cab rides to just about anywhere in the Washington, DC area.

Today, the practical support to Veterans and their families while recuperating in the hospital continues. But understanding the stress and strain of caregiving, YRF hosts a three-day retreat for caregivers, which is offered three times per year. The all-expense-paid getaways provide much-needed respite and mutual support for caregivers from around the country. The retreat was the brainchild of a long-term advocate for military families, two fellow military spouses, and coordinator of YRF's family caregiver program, who is also the wife and caregiver of a wounded soldier.

Instead of planning back-to-back activities, the retreats are a time for caregivers to relax and nurture themselves. Caregivers are truly in charge of their own agenda. Times are blocked out for naps, reading, craft-making, a relaxed walking tour, and good eating. Caregivers could go out, as a group, to a nice restaurant or, they could choose to order room service and eat in bed. The retreats are so relaxing that caregivers often wish they could stay another day. One retreat participant shared, "My family has to be thinking, oh, my gosh, she's so much nicer now – that's what a good night's sleep will do! We should send her away more often!" Retreat participants bond during the retreat and have formed a Facebook group.

The most remarkable fact about the retreat is that 80 cents of every dollar spent has gone directly to programs and services for caregivers and Veterans. The small staff is supported by a volunteer force of more than 1,300.

## Federal and State Respite Funding

Increasingly, federal, state and local agencies, and Veterans' and other non-profit organizations are acknowledging the unique needs of caregivers of Veterans. Following is a summary of the major sources of funding for respite.

### *Programs Specifically for Veterans*

The Veterans Health Administration of the US Department of Veterans Affairs (VA) provides a comprehensive program for caregivers of Veterans through its VA Caregiver Support Program. Passing of the Caregiver and Veterans Omnibus Health Services Act in 2010 significantly expanded the program. The Program of Comprehensive Assistance for Family Caregivers supports family caregivers of post-9/11 Veterans and the Program of General Caregiver Support Services expanded services for caregivers of Veterans with disabilities from all eras. The VA Caregiver Support Program provides Caregiver Support Coordinators in each VA Medical Center, a Caregiver Support Line, caregiver education and training, a comprehensive website and peer support programs in addition to respite services. The VA's respite services are available through the following benefits programs and more information can be found at <http://www.caregiver.va.gov>.

- **The Program of Comprehensive Assistance for Family Caregivers** began in May 2011. It offers a variety of services and supports to caregivers of Veterans injured in the line of duty on or after September 11, 2001, including a monthly stipend, travel expenses, access to health care insurance, mental health services, and respite. The injury must require personal care services for at least six months. Eligible caregivers are family members who live with the Veteran and must attend training to demonstrate the ability to care for him or her. For more information: [http://www.caregiver.va.gov/support/support\\_benefits.asp](http://www.caregiver.va.gov/support/support_benefits.asp)
- **The Caregiver Support Network**, created through a partnership of the Department of Veterans Affairs Voluntary Service (VAVS) and the Office of Care Coordination, offers volunteer

support to assist primary caregivers of Veterans with multiple injuries, TBI and/or spinal cord injury. Volunteers are matched with Veterans in their neighborhoods to develop long lasting friendships with the Veteran and caregiver. This program is available through local VA Health Centers. Screened and trained volunteers assist caregivers by reducing their workload and providing companionship. Volunteers offer

## Wounded Warriors Family Support

<http://www.wwfs.org/respite-care/respite-care>

The mission of Wounded Warriors Family Support is to assist families of service members and Veterans with service-related injuries. The organization supports caregivers as they keep their families intact and focus on their own health. The **Caregiver Respite Program** provides respite in the form of weekend retreats, in-home respite and supplemental services nationwide to the caregivers and families of wounded war Veterans. The program also enrolls caregivers in the Department of Veterans Affairs Caregiver Support Services and links them with other agencies offering resources and support.

To be eligible for services, the Veteran must have dependent children and a Purple Heart, recognition for being wounded in action. If they have not been awarded a Purple Heart, they must meet the following requirements:

An 80%–100% combined disability rating with a single physical disability rating of 30% or greater for injuries sustained during combat in one of the following specific categories:

- Blindness/loss of vision
- Severe Burns
- Spinal cord injury/paralysis
- Traumatic Brain Injury



respite care in addition to friendly visiting, writing and reading letters, and telephone companionship. Download brochure at [http://www.volunteer.va.gov/docs/Caregiver\\_Brochure.pdf](http://www.volunteer.va.gov/docs/Caregiver_Brochure.pdf)

- **Geriatrics and Extended Care** provides services for Veterans who are elderly and have complex needs, and Veterans of any age who need daily support and assistance. Through the Home and Community Respite Program, respite is provided through home health aides, adult day health centers or community living centers. Services

### Legacy Corps Respite

<http://sph.umd.edu/department/hlsa/grants/research-project/legacy-corps-health-and-independent-living>

Legacy Corps operates in 15 sites in 11 states under the auspices of the University of Maryland, Department of Health Services Administration with funding from the Corporation for National and Community Service. Legacy Corps, in collaboration with the American Legion Auxiliary, Vietnam Veterans of America, Fisher House Foundation, and Easter Seals National Veteran Caregiver Training Division, uses highly trained volunteers to provide caregiver support services, including in-home respite care, caregiver education, and linkages to other community support resources, to Veterans and military families. Volunteers commit to serving 450 hours in a one-year period (approximately 10 – 12 hours per week) and are selected after meeting eligibility criteria. Volunteers meeting their service goals receive skills training, a small monthly living allowance, and an educational award. Legacy Corps has demonstrated that its services reduce family caregiver stress and improve caregiver perceptions of their own emotional health.

are available up to 30 days per year. VA Home Hospice Care respite services are available to terminally-ill Veterans. For more information: [http://www.va.gov/GERIATRICAL/Guide/LongTermCare/Respite\\_Care.asp](http://www.va.gov/GERIATRICAL/Guide/LongTermCare/Respite_Care.asp)

- **Veteran Directed Home and Community-Based Services (VD-HCBS)** allow Veterans of all ages and their caregivers to choose and manage services and supports in their home as an alternative to a long-term care facility. Veterans at risk of nursing home placement are eligible. The program is a collaboration between the VA and the Administration for Community Living and is currently offered at 55 Veterans Affairs Medical Centers (VAMC) in collaboration with over 110 Aging/Disability Network providers. To date this program has served over 2900 Veterans including both older and younger Veterans with complex needs and those transitioning back to the community from hospitals and nursing home stays. Veterans enrolled in the VD-HCBS Program receive a budget based on their needs. Veterans receive support from a person centered counselor employed by a local Area Agency on Aging, Aging & Disability Resource Center or Center for Independent Living as well as financial management services to ensure that the Veteran's employees are paid timely and that he or she is being supported to prevent unnecessary hospital admission or nursing home placement. Respite is a core service supported by the funding. For more information on VD-HCBS: [http://www.va.gov/GERIATRICAL/Guide/LongTermCare/Veteran-Directed\\_Care.asp#](http://www.va.gov/GERIATRICAL/Guide/LongTermCare/Veteran-Directed_Care.asp#) The VA is looking to expand a pilot program that focuses solely on self-directed respite. For more information on Veteran Directed Respite: [http://www.arch.memberlodge.org/Resources/Documents/2013%20National%20Respite%20Conference/PPTs/Merle-Edwards\\_2F.pdf](http://www.arch.memberlodge.org/Resources/Documents/2013%20National%20Respite%20Conference/PPTs/Merle-Edwards_2F.pdf)
- Funding to pay for respite may also be available to Veterans through **Aid and Attendance and Housebound Benefits**. This is a paid benefit of up to \$2,900 added to the Veteran's pension that can be used in anyway, including the purchase of respite services. Eligible beneficiaries are at least

65 years old or permanently and totally disabled if they are younger. This includes Veterans who are blind or confined to the bed. For more information: [http://www.va.gov/GERIATRICAL/Guide/LongTermCare/Paying\\_for\\_Long\\_Term\\_Care.asp#](http://www.va.gov/GERIATRICAL/Guide/LongTermCare/Paying_for_Long_Term_Care.asp#)

- Each branch of the **Department of Defense** offers programs for military caregivers. These “Wounded Warrior” programs focus on coordinating nonmedical care and assistance. Although they may not provide the care directly, they will help families connect with respite care and other support services. For more information: <http://warriorcare.dodlive.mil>

### **Other Federal Programs**

#### **National Family Caregiver Support Program**

The National Family Caregiver Support Program (NFCSP) provides respite as well as caregiver support. The Administration on Community Living reports that over 64,000 caregivers have received 6.8 million hours of respite since the program’s inception in 2000. The program is administered through the aging network and offers respite services either in the home, the community through adult day services or community-based agencies, or in institutional settings. Caregivers of Veterans can take advantage of these services if they meet the following eligibility criteria:

- Adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older;
- Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer’s disease and related disorders;
- Grandparents and other relatives (not parents) 55 years of age and older providing care to children under the age of 18; and
- Grandparents and other relatives (not parents) 55 years of age and older providing care to adults age 18-59 with disabilities.

### **Medicaid**

Veterans can qualify for the Medicaid Hospice Benefits and Home and Community Based Waiver programs while receiving benefits from the VA if they meet the income and eligibility criteria. Medicaid Hospice Benefits provide respite for up to five days at a time for Veterans receiving in-home hospice. Home and Community Based Services Waivers may cover respite if the service is required to keep the Veteran from nursing home placement. Each state’s eligibility criteria and funding for waivers are different. In 2012, at least 11 states offered respite using waivers that specifically mention traumatic brain injury as a condition of eligibility (GA, IL, IN, KY, MA, MS, NM, NY, ND, PA and SC), and two states fund respite through Medicaid waivers that specifically mention spinal cord injury (MS, SC) (ARCH National Respite Network and Resource Center, 2012). Forty-four states and the District of Columbia offer respite for caregivers of individuals with dementia through HCBS waivers (ARCH National Respite Network and Resource Center, 2014). Many states have modified their Medicaid waivers as they move toward managed care for long-term services and supports. For more information on Medicaid waivers by state: [http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers\\_faceted.html](http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html)

States can also offer respite services under a State Plan Home and Community-Based Services (HCBS) 1915(i) benefit. People must meet State-defined criteria based on need and typically get a combination of acute-care medical services and long-term services (e.g. respite, case management, supported employment and environmental modifications). States can limit this benefit to individuals with specific disabilities or conditions. Veterans may be eligible if they meet state-defined eligibility criteria, but they do not have to require a nursing home level of care. For more information: <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/home-and-community-based-services-1915-i.html>

## Lifespan Respite Care Program

This program seeks to meet the respite needs of caregivers of both children and adults with special needs by supporting coordinated systems of community-based respite care services within the states. Some Lifespan Respite grantees provide limited respite services or financial assistance to underserved populations in their states for both planned and emergency respite. State Lifespan Respite grantees must work in partnership with a state respite coalition. VA Caregiver Coordinators have become involved with many state respite coalitions to help improve access to and quality of respite services and options for caregivers of Veterans. For Lifespan Respite state contacts, see <http://archrespite.org/lifespan-programs>.

Information on additional federal programs that may provide respite support for caregivers of Veterans and military families in some states can be found in ARCH's *Federal Funding and Support Opportunities for Respite* guide at [http://www.lifespanrespite.memberlodge.org/Federal\\_Funding\\_Guide](http://www.lifespanrespite.memberlodge.org/Federal_Funding_Guide).

## State and Local Respite Assistance

Across the states, the number and nature of state and locally supported services for caregivers vary. Veterans and their caregivers may or may not qualify for these services because of age, income or disability restrictions. In an attempt to ascertain the availability of these services to caregivers of Veterans, a comprehensive examination of state caregiving services for military families was conducted by the Rand Corporation in 2014. Rand identified 127 programs across the country targeting military family caregivers. Most of these organizations offered education and training, social support, and helping hand services, while only nine offered respite care, including the VA Caregiver Support Program (Rand Corporation, 2014).

Some private state or local programs may offer respite for which the Veteran may be eligible, such as Easter Seals or Wounded Warrior Family Support. Caregiver retreats are offered by organizations such as the Independence Fund and the Yellow Ribbon

Fund. Caregivers may also receive respite through private home care agencies and adult day facilities, although this may not be the primary intention of such programs. For example, the Wounded Warriors Program provides in-home physical therapy for severely injured Veterans. Caregivers can take a break while the Veteran is being treated by the therapist. Also, some private organizations provide emergency financial assistance that can be used to pay for respite care (Ramchand, et al., 2014).

## Recommended Strategies for Lifespan Respite Grantees and Partners to Improve Access to Respite Services for Caregivers of Veterans and Military Families

- 1 Include Caregiver Coordinators from local VA Medical Centers, Elizabeth Dole Caregiver Fellows and other family caregivers of Veterans, and Veterans themselves, in Lifespan Respite stakeholder groups, including state respite coalitions. Seek out their guidance to identify gaps in planned and emergency respite services for Veteran populations. The Dole Caregiver Fellows Program is an initiative of the Elizabeth Dole Foundation. (See Veteran and Military Respite and Caregiver Resources on page 13.)
- 2 Expand and enhance outreach and education efforts to family caregivers of Veterans to provide information on the importance of respite and how to access it within and outside the VA system. Also provide information to Veterans about why respite is important for family caregivers to increase their acceptance of respite.
- 3 Confer with Veterans and their family caregivers to develop new or alternative respite services to meet their unique needs.
- 4 Consider setting aside funding in any planned or emergency respite voucher initiatives for caregivers of Veterans, especially for caregivers of post 9/11 Veterans, who may not be eligible for any other funding source.

- 5 In ongoing efforts with the faith-community and other volunteer organizations to expand or enhance respite options, include the Veteran and their family caregivers among those targeted for receipt of respite services.
- 6 Engage in cross training with the local VA Medical Center and other Veterans' groups to learn more about the respite needs of the Veteran population and to ensure that they, in turn, are aware of the Lifespan Respite program, the state respite coalition, and all respite opportunities in local communities.
- 7 Confer with experts in military caregiving and culture from local Veteran and military family and caregiver groups, such as those at Paralyzed Veterans of America, and with local VA Caregiver Coordinators at VA Medical Centers and others when developing new training curricula or in recruiting respite workers and volunteers. Refer to the VA-DoD's online course, *Military Culture: Core Competencies for Health Care Professionals* at <http://www.va.gov/HEALTH/NewsFeatures/2015/July/Helping-Your-Provider-Understand-Military-Culture.asp>.
- 8 Given that caregivers of Veterans living in rural areas have higher levels of depression than caregivers living in urban or suburban areas, the need for respite here may be especially pronounced. Partner with local offices of the US Department of Agriculture's Cooperative Extension Service or the faith community to research and develop new rural respite options. For examples of rural respite options, see the *ARCH Fact Sheet: Respite for Rural Family Caregivers: Overcoming the Challenges* at [http://archrespite.org/productspublications/arch-fact-sheets#FS\\_35](http://archrespite.org/productspublications/arch-fact-sheets#FS_35).

## Summary

Caring for Veterans may result in emotional, physical and financial stress for the whole family. When the Veteran is dealing with neurological conditions, amputation, PTSD and TBI, as many post-9/11 Veterans are, the burden on the caregiver can be tremendous. Respite care is a way to provide some relief to caregivers and strengthens their ability to continue in that role. Yet our current system is in jeopardy. The labor shortage of trained respite workers is daunting, making it difficult for families to find suitable services. Eligibility requirements are confusing and limiting as most programs focus on seniors, leaving the caregivers of younger Veterans ineligible. Emergency services are sorely lacking.

In recent years, the federal government and a few national non-profit organizations have taken the lead in focusing attention on the needs of caregivers of Veterans. However, the specific respite needs of these caregivers are not being fully met.

State Lifespan Respite grantees and partners, including State Respite Coalitions, should consider alternative strategies to expand respite options for Veterans and their caregivers. Working with existing Veteran organizations and faith communities may be a tactic for recruiting volunteers to serve as respite providers.

Whether in the home or in the community, providers need to be trained to ensure a positive experience for both the Veteran as well as the caregiver. Cross training of respite workers and volunteers to meet this need of a diverse population of persons with disabilities is imperative.

## Veteran and Military Respite and Caregiver Resources

### Caring for Military Families: The Elizabeth Dole Foundation

<http://www.elizabethdolefoundation.org>

The mission of *Caring for Military Families: The Elizabeth Dole Foundation* is to “uplift American military caregivers by strengthening the services afforded to them through innovation, evidence-based research, and collaboration.” They set out to accomplish this by conducting evidence-based research on the needs of military caregivers; empowering caregivers; driving innovation; promoting collaboration; and raising awareness. Foundation programs include the Elizabeth Dole Fellows Program, Innovation grants, Caregiver Community Program and the Coalition for Military Caregivers. A Respite Impact Council is one of seven councils established through the Coalition for Military Caregivers.

### Christopher and Dana Reeve Foundation, Paralysis Resource Center

[http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.6605235/k.3533/Military\\_and\\_Veterans\\_Program.htm](http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.6605235/k.3533/Military_and_Veterans_Program.htm)

The Reeve Foundation assists service men and women, whether they are paralyzed through combat related, service related, or non-service related events. Their Military and Veterans Program (MVP) has dedicated funds to assist military and veteran focused nonprofit organizations. The Resource Center has MVP Information Specialists and written resource materials for the veteran and military population.

### Department of Defense (DoD) Caregiver Resources Office of Warrior Care Policy

<http://warriorcare.dodlive.mil/caregiver-resources>

The Department of Defense (DoD) provides resources and information exclusively for military caregivers who assist wounded, ill and injured Service members with activities of daily living. DoD’s Military Caregiver Support includes the Military Caregiver PEER Forum Initiative (Personalized Experiences, Engagement, and

Resources), the Caregiver Resource Directory, monthly Military Caregiver Virtual Forums, Military Caregiver Webinars, events and specialized resources.

### DSTRESS Line

The DSTRESS Line was developed by the Marine Corps to provide professional, anonymous counseling for Marines, attached Sailors, and families. Call 1-877-476-7734 or visit the US map to find services at <http://www.dstressline.com/index.cfm/resources/#.VaLT2PIVhBc>.

### Fisher House

<https://www.fisherhouse.org>

Fisher Houses provide military families housing close to a loved one during hospitalization for an illness, disease or injury. The Fisher House Foundation joins with Newman’s Own and Military Times (Gannett Government Media Corporation) to provide grants to organizations with creative military quality of life improvement plans.

### Independence Fund

<http://www.independencefund.org/page/Caregivers>

The Independence Fund was founded with the mission to provide wounded Veterans, their families and caregivers with services and resources that they were not otherwise receiving. They periodically hold retreats to provide respite for caregivers.

### Lifespan Respite Programs

<http://archrespite.org/lifespan-programs>

Funded by the Administration for Community Living, US Department of Health and Human Services, State Lifespan Respite Programs or Projects are run by a designated state government lead agency, which works in collaboration with a State Respite Coalition and an Aging and Disability Resource Center. Their purpose is to implement statewide systems of coordinated, community-based respite for family caregivers caring for individuals with special needs of all ages. For State Respite Coalition contacts, visit <http://archrespite.org/state-respites-coalitions>.

### **Military OneSource**

<http://www.militaryonesource.mil>

Military OneSource is a confidential Department of Defense-funded program providing comprehensive information on every aspect of military life at no cost to active duty, National Guard, and reserve members, and their families. Information includes, but is not limited to, deployment, reunion, relationships, grief, spouse employment and education, parenting and childhood services.

### **National Center for PTSD**

<http://ptsd.va.gov/public/family/effects-ptsd-family.asp>

Resources on identifying, treating and coping with Posttraumatic stress disorder (PTSD) are offered.

### **National Military Family Association**

<http://www.militaryfamily.org/info-resources/wounded-caregivers>

NMFA strives to be the voice of military families. The organization provides a variety of services and supports, including military spouse scholarships, summer camps, family retreats and the MyMilitaryLife App.

### **No Wrong Door Systems (NWD)**

<http://acl.gov/Programs/CIP/OCASD/ADRC/index.aspx>

NWD is a single statewide system of access to LTSS for all populations and all payers. To date, ACL has funded 54 out of 56 states and territories to implement NWD activities. Nationwide 530 local NWD systems are in place actively serving older adults and persons with disabilities. The NWD System functions include: 1) Public Outreach and Coordination with Key Referral Sources; 2) Person Centered Counseling; 3) Streamlined Access to Public LTSS Programs; and, 4) State Governance and Administration. NWD is supported by the Administration for Community Living (ACL), Centers for Medicare and Medicaid Services (CMS), and the Veterans Health Administration (VHA). To find a local NWD system, visit <http://www.adrc-tae.acl.gov/tiki-index.php?page=ADRCLocator>.

### **Paralyzed Veterans of America (PVA)**

[http://www.pva.org/site/c.ajlRK9NjLcJ2E/b.6305401/k.27D1/Paralyzed\\_Veterans\\_of\\_America.htm](http://www.pva.org/site/c.ajlRK9NjLcJ2E/b.6305401/k.27D1/Paralyzed_Veterans_of_America.htm)

PVA advocates for better health care and benefits, satisfying careers, caregiver supports, and a cure for paralysis. They also provide assistance with accessing adaptive sports and provide education for clinicians about spinal cord injury. PVA has 72 National Service Offices and 34 chapters serving all 50 states, the District of Columbia and Puerto Rico. To find a local service office or chapter, visit [http://www.pva.org/site/c.ajlRK9NjLcJ2E/b.6452325/k.A0ED/Chapters\\_and\\_NSOs.htm](http://www.pva.org/site/c.ajlRK9NjLcJ2E/b.6452325/k.A0ED/Chapters_and_NSOs.htm)

### **Rosalynn Carter Institute for Caregiving (RCI) – Operation Family Caregiver**

<http://www.operationfamilycaregiver.org>

RCI's Operation Family Caregiver (OFC) provides confidential one-on-one support and training for caregivers of newly returning service members and Veterans with traumatic brain injury, posttraumatic stress, and/or physical disability. Specially trained coaches who work for local community-based agencies work with the caregiver to customize a 16- to 24-week program that is unique to each family. Caregivers who have completed the program report greater life satisfaction, reduced depression, fewer health complaints, and increased ability to take care of their families.

### **VA Caregiver Support Program**

<http://www.caregiver.va.gov>

The VA website contains links to all of the caregiver support programs administered by the US Department of Veterans Affairs, training and education, and other resources and materials for and about caregivers of Veterans. Caregivers and others can also call the Caregiver Support Line at 1-855-260-3274 or link to their local VA Caregiver Support Coordinator from the website to find services and supports in their communities.

### **Wounded Warriors Family Support**

<http://www.wwfs.org>

The organization supports families of those who have been wounded, injured or killed during

combat operations and maintains a Caregiver Respite Program. Applications and other resources for respite are available on this site.

### **Wounded Warriors Project – Independence Program**

<http://www.woundedwarriorproject.org/programs/independence-program.aspx>

The Independence Program is designed for warriors who rely on their families and/or caregivers because of moderate-to-severe brain injury, spinal-cord injury, or other neurological conditions. The Program provides support and training for involvement in social and recreational activities; wellness; volunteer work; education and other life skills through an individualized plan at no cost to the family.

### **eXtension for Military Caregivers**

<http://www.extension.org/pages/60576/military-family-caregiving#.VaKz3PIVhBc>

The eXtension website was created by the United States Department of Agriculture (USDA), Cooperative Extension System to provide resources for caregivers. Resources specifically for military families were developed as a joint venture with the Department of Defense. Webinars, caregiving tips and other resources can be found here.

### **Veteran Caregiver Training and Support Resources**

A number of programs provide education and training to providers and caregivers of Veterans. Increasing a caregiver's knowledge, skills and coping ability will result in better care for the Veteran and less strain on the caregiver. Following are a few examples of caregiver training programs designed for military caregivers and caregivers of Veterans.

### **Blue Star Families – Caregivers Empowering Caregivers**

As a membership organization, Blue Star Families has 46 chapters around the world and its members include active duty, National Guard, Reserve,

wounded, transitioning service members, Veterans and civilians. Started in 2009 by a group of military spouses, Blue Star Families works to strengthen military families through outreach and involvement with national and local organizations, civilian communities and government entities. One initiative, Caregivers Empowering Caregivers, provides resources, support and tools for caregivers, including a webinar series. For more information: <https://www.bluestarfam.org/resources/caregivers-empowering-caregivers>

### **Building Better Caregivers™ (BBC) and Caregiver Self-Care Courses**

Two popular programs are administered by the VA and the National Council on Aging. Building Better Caregivers™ is a free, six-week online workshop for groups of family caregivers of Veterans developed by Stanford University. It reduces caregiver stress and depression by teaching important skills like stress and time management, dealing with emotions and healthy lifestyle choices. It also covers conditions that are frequently found among Veterans such as dementia, memory problems, traumatic brain injury, posttraumatic stress disorder, or any other serious injury or illness. Twenty to 25 caregivers complete the course together, participating two to three times per week. An online Alumni Community allows caregivers to stay connected with each other after the program has been completed. For more information: <http://www.va.gov/health/NewsFeatures/2013/August/Are-You-a-Caregiver-for-a-Veteran.asp>

Caregiver Self-Care Courses are four, face-to-face educational courses for caregivers. The three-hour classes focus on stress management, problem solving, self-care and utilization of technology. Participants receive a workbook and a relaxation CD. Veterans who are caregivers to an aging or disabled spouse, parents or child can also attend. For more information: [http://www.caregiver.va.gov/strong/strong\\_yourself.asp](http://www.caregiver.va.gov/strong/strong_yourself.asp)

### **Easter Seals Training for Caregivers**

Easter Seals offers training for caregivers under a contract with the US Department of Veterans

Affairs. Easter Seals partners with Atlas Research, Axiom Resource Management, Family Caregiver Alliance, National Alliance for Caregiving, and the National Alliance for Hispanic Health on this project. Implemented in April 2011, the classes cover caregiver self-care, home safety caregiver skills, Veteran personal care, managing difficult behaviors, and support resources. Over 25,000 caregivers have received the training. Respite care is provided so caregivers can attend the training. For more information: <http://www.easterseals.com/our-programs/military-Veterans/Veterans-caregiver-training.html?referrer=https://www.google.com>

Easter Seals also offers a series of webinars offering helpful tips and tools to support military caregivers. This effort is funded by Newman's Own Foundation and is undertaken in partnership with Family Caregiver Alliance, the National Alliance for Caregiving, the USO, Caregiver Action Network, the Rosalynn Carter Institute for Caregiving, and Atlas Research. Archived webinars can be found at: <http://www.easterseals.com/explore-resources/for-caregivers/2014-military-caregiving-webinar-series.html>

### **Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans**

This caregiver training series is offered by the Defense and Veterans Brain Injury Center. The sessions are a source of information and support for caregivers of service members and Veterans with moderate to severe TBI. It covers the effects of TBI – cognitive, emotional, behavioral, and physical. For more information: <http://dvvbic.dcoe.mil/family-caregiver-curriculum>

### **USO Caregiver Seminars**

The USO offers educational sessions and an annual caregiver conference. Topics range from resiliency, compassion fatigue, and sexual intimacy. Caregivers learn how to better care for themselves and their loved one. For more information: <http://www.uso.org/Programs/Warrior-and-Family-Care/Behavioral-Health-Support.aspx>

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