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9 STEPS TO RESPITE CARE for Military Caregivers: *A Pathway to Get the Break You Deserve*

Introduction

Are you a military family caregiver?

You are called a caregiver if you help or support another person in need due to physical or mental, cognitive or functional limitations, whether you help full-time or as time permits. The person needing help may live in their own home, with you or in a residential setting.

Military and Veteran Caregivers may face special challenges. Sometimes, Veterans have unique physical, emotional and behavioral conditions that require specialized care. For example, younger Veterans may have traumatic brain injury, spinal cord injuries, amputations and post-traumatic stress disorder. Aging Veterans also may be diagnosed with dementia, including Alzheimer's disease. Providing care for these Veterans can be complicated and challenging.

You and members of your family may feel overwhelmed and stressed while your Veteran may be angry or depressed. Most likely, your health and well-being are impacted by all that caregiving entails. Therefore, identifying yourself as a "caregiver" is important for there are numerous resources available to help you.



▶▶▶ This fact sheet is a guide for getting the respite care you deserve. By reading it, you will have a better understanding of the resources that are available, what you can expect and how to select a high-quality service that best meets the needs of your family.



►►► Tools are available to assess your own needs including the following that are specifically for caregivers of Veterans:

- **Caregiver Self-Assessment Worksheet**, Veterans Health Administration, U.S. Department of Veterans Affairs (VA) www.va.gov/GERIATRICS/Guide/LongTermCare/Caregiver_Self_Assessment.pdf
- **“Building on the Small Moments of Self-Care” Self-Care Assessment and Daily Attention Diary**

Overview, VA Caregiver Support Program www.caregiver.va.gov/pdfs/DailyAttentionDiary/SelfCareAssessmentandDailyAttentionDiaryOverview.pdf

This tool is from the general caregiving community:

- **Time for Living and Caring: Making Respite Services Work for You** can help you assess your respite needs and plan your respite time. www.archrespice.org/images/docs/Outside_Reports/Lund_TLCRespiteBrochure_2014.pdf

STEP 1

Understanding Respite Care

It is important for you to be aware of a resource called respite care. Respite services provide you with a much needed break away from your caregiving responsibilities. By taking a break, you will become less stressed, better rested and renewed. Your loved one may also benefit from a change in routine. Sometimes feelings of guilt or anxiety about leaving your family member may keep you from seeking respite in a timely way. Families are encouraged to start using respite care at the beginning of their caregiving experience and on a regular basis to avoid these feelings of guilt, exhaustion, isolation and burnout.

STEP 2

Types of Respite Care Available

Respite care is offered in a variety of ways. You can receive a break for a few hours, a few days or even a few weeks. Services for the Veteran may take place in the home, or outside the home, in a community or faith-based agency or organization, at an adult day care facility, in a hospital, or in a residential setting. Other family members, friends or neighbors may also be available to provide informal respite opportunities.

Paid care may be provided by a home health agency or other community-based program, or it could be someone you hire on your own. Volunteer services are available in many communities. Some respite service organizations support people within a specific age bracket or persons with specific conditions. In some cases, emergency respite services are available.

Non-traditional or more informal respite services may allow volunteers or paid respite workers to accompany the Veteran to community activities. Some families build respite cooperatives where caregivers trade off providing respite services to one or more Veterans at home or in the community.

►►► A very useful video, **ABC's of Respite: Caregiver Support**, developed by PsychArmor Institute and narrated by Meg Kabat, National Director of the Caregiver Support Program at the U.S.



Department of Veterans Affairs, talks about formal and informal respite options and provides useful tools for talking to your Veteran about the importance of respite to you, your family and

your relationship. To access the video, visit www.psycharmor.org/lessons/caregiver-support-10-min.

**STEP
3**

Where Do I Find Services?

There are several ways to find respite. Some programs are specifically for military caregivers and others are provided to the general public. Below is an overview of places to contact regarding the respite services that are available in your community.

Respite Programs for Military Caregivers

For Post 9/11 Veterans

- The **VA Program of Comprehensive Assistance for Family Caregivers** provides respite and additional support for caregivers of post-9/11 Veterans. Visit www.caregiver.va.gov or call the Caregiver Support Line: 1-855-260-3274.

For Veterans from All Eras

- The **VA Caregiver Support Program** offers up to 30 days of respite care per year for eligible Veterans. The care is provided in the home, at a VA facility or an adult day care center. Respite is a covered benefit for all Veterans enrolled in the VA health care system or who are eligible for VA health care without the need to enroll for such care.
- The **VA Voluntary Service Office** offers volunteer support to assist primary caregivers of Veterans with multiple injuries, TBI and/or spinal cord injury. Screened volunteers provide respite for the caregiver and companionship for the Veteran. This service is not available in every state. Ask your local VA Caregiver Coordinator if the service is offered in your area.
- Through the **VA Geriatrics and Extended Care Program**, caregivers of Veterans with complex care needs can participate in the Home and Community-based Services Respite Program. See www.va.gov/GERIATRICS/Guide/LongTermCare/Respite_Care.asp for more information.

- Veterans with medical needs or a mental or physical disability who are at least 65 years old, or permanently and totally disabled if they are younger, may qualify for the **VA Aid and Attendance and Housebound Benefit**, which increases the Veteran's pension by up to \$2,900. Single Veterans and surviving spouses may be eligible for smaller payments. Caregivers can use these funds to purchase respite services. This includes Veterans who are blind or confined to the bed. For eligibility, contact a VA Regional Office on the U.S. Department of Veterans Affairs website at www.va.gov/directory/guide.

- In the **Veteran-Directed Home and Community Based Services Program (VDHCBSP)**, Veterans who are eligible to live in a long-term care facility, but choose to remain in the community, are provided with a flexible budget to support their daily needs. Respite care can be included in their budget. To find a local VDHCBSP Program near you, see www.acl.gov/programs/veteran-directed-home-and-community-based-services/veteran-directed-home-community-based.

Other government-funded respite programs or information for military families include:

- The **Exceptional Family Member Respite Program** provides respite care when a family member has special needs or disabilities. "Family member" includes adults with special medical needs or children 21 and under with a special educational need. Child Care Aware of America partners with agencies near military installations to ensure that families who serve in the Navy or Air Force receive high quality respite. For more information, see www.usa.childcareaware.org. To locate respite services

▶▶▶ Respite services for Veterans are offered by the **US Department of Veterans Affairs (VA)** and other organizations. In your search, you should start by contacting your local VA Caregiver Coordinator at the VA Medical Center closest to you to learn about the programs available in your area. To do so, visit the VA Caregiver Support website at www.caregiver.va.gov or call the Caregiver Support Line: 1-855-260-3274.



for the other branches of the military, contact the Exceptional Family Member Program office near you by visiting MilitaryINSTALLATIONS at www.militaryinstallations.dod.mil or contact Military OneSource at 800-342-9647 and ask for a referral to a special needs consultant.

- Each branch of the **Department of Defense** through the **Caregiver Resources Office of Warrior Care Policy** offers programs for military caregivers. Some may offer respite while others may provide referrals to local respite programs. <http://warriorcare.dodlive.mil/caregiver-resources/>

Many states and local communities offer respite services in the private sector specifically for Veterans or military families.

- Organizations such as **Easterseals** www.easterseals.com; the **Independence Fund** www.independencefund.org; and the **Yellow Ribbon Fund** www.yellowribbonfund.org/family-caregiver-support provide respite that Veterans can access, or respite retreats for military caregivers, if eligible.
- **Wounded Warriors Family Support** provides the Caregiver Respite Program in the form of weekend

retreats and in-home respite for persons caring for Veterans who have service-related injuries and dependent children. www.wvfs.org/respite-care/respite-care

- The **Hero Miles Program** offered by the Fisher House Foundation will provide donated airline miles to fly a relative or friend to your location to provide respite care if you have no family members in your area. To qualify, you have to participate in the VA's Program of Comprehensive Assistance for Family Caregivers. www.fisherhouse.org/programs/hero-miles
- **Legacy Corps** is available in 11 states under the auspices of the University of Maryland, Department of Health Services and its partners. Volunteers provide in-home respite for 10–12 hours per week along with other services to military caregivers. www.sph.umd.edu/departments/hlsa/ca/history-and-mission-legacy-corps

Finding Respite in the General Population

These programs are available to help all caregivers. You will need to contact the organization listed for further details:

- The **National Family Caregiver Support Program** provides respite and other caregiver support to caregivers assisting someone 60 and older, an Alzheimer's patient of any age, or to a grandparent or relative caregiver (age 55+) of a minor child, or to an older parent or relative caregiver (age 55+) of an adult with disabilities. You can access services through your local Area Agency on Aging (AAA). To find the AAA nearest you, contact the **Eldercare Locator** at www.eldercare.gov or call 1-800-677-1116.
- **No Wrong Door (NWD) Systems** established jointly by the Administration for Community Living, the Centers for Medicare and Medicaid Services and the Department of Veterans Affairs are working in every state to make it easier for all people needing long-term services, including respite, to





get the support they need. To find a NWD system (including Aging and Disability Resource Programs) near you, visit the Eldercare Locator at www.eldercare.gov or call 1-800-677-1116. Additional information about No Wrong Door Systems can be accessed at nwd.acl.gov.

- The **Lifespan Respite Care Program** is available in some states to help caregivers of children and adults get respite services. Some states provide planned and emergency respite services to persons who are unserved by other programs. Lifespan Respite programs or their State Respite Coalition partners may help you find respite providers or funding resources to help you pay for respite. For Lifespan Respite state contacts, see www.archrespite.org/lifespan-programs. For State Respite Coalition contacts, see www.archrespite.org/state-respite-coalitions. If your state does not have a State Lifespan Respite Program or a State Respite Coalition, you can visit the **ARCH National Respite Locator Service (NRLS)** at www.archrespite.org/respitelocator to find respite programs in your area.

STEP 4

How Will I Pay for Respite?

Fees for the VA respite programs described above depend on the Veteran's status. In many cases, respite will be free. In some cases, however, the Veteran will be required to pay a co-payment based on his or her service-connected disability status and financial information. Similarly, Medicaid respite is for caregivers of older adults or persons with specific disabilities or conditions that meet income guidelines. Services are delivered without charge. In addition, some volunteer and public respite programs are free for Veteran caregivers.

Possible Funding Sources for Respite

- **TRICARE Respite for Injured Service Members:** Respite care is available to primary caregivers of service members who have a serious injury that has resulted in or may result in a physical disability or an extraordinary physical or psychological condition. The condition may be so severe that the service member is left homebound. TRICARE considers you homebound if you can't leave your home without a lot of effort. For more

information see www.tricare.mil/CoveredServices/IsItCovered/RespiteCare.

TRICARE's ECHO supplements health insurance for military families who have family members with special needs. Respite is available as a covered benefit. Contact your local Beneficiary Counseling and Assistance Coordinator, TRICARE Service Center, or their regional contractor for more information at www.tricare.mil/Plans/SpecialPrograms/ECHO.aspx.

- **Medicaid:** Veterans and members of military families with special needs may qualify for respite services through Medicaid in some states if they meet eligibility criteria. Contact your local Medicaid office by visiting www.medicaiddirectors.org/about/medicaid-directors for details about eligibility and providers under the Medicaid state plan and the Hospice Benefit. To find out more about specific Medicaid waivers that pay for respite in your state, click on your state on the ARCH *US Map for Respite Funding and Caregiver Supports*



at www.archrespite.org/respitelocator/respite-locator-service-state-information-map and scroll down to “Medicaid Waivers”.

- **State Funded Respite Programs:** Your state may provide respite through state-funded respite, caregiver or family support programs for children and/or adults with developmental and intellectual disabilities, special medical needs or for older family members with Alzheimer’s. Check with your State Lifespan Respite program for more information or visit the ARCH *US Map for Respite Funding and Caregiver Supports* at www.archrespite.org/respitelocator/respite-locator-service-state-information-map and scroll down to “Other Possible Public Funding Sources”.
- **Consumer-Directed Respite:** The Veteran Directed Home and Community Based Services programs and some Lifespan Respite Programs, state-funded respite programs, and Medicaid waivers, provide respite vouchers or a service budget that allow you and/or the Veteran to hire, train and pay your own respite providers. These programs are sometimes known as cash and counseling, or consumer or participant-directed services, but program names differ from state to state.
- **Private Pay:** If none of the options listed above work for you, you may choose to pay for private respite services. In limited cases, there may be respite care coverage in some long-term care insurance policies. According to the 2017 Genworth Cost of Care Survey, typically homemakers and home health aide companies charge about \$15 to \$20 per hour and adult day health averages \$70 per day. Rates vary by where you live.

For additional information on federal funding sources to help you pay for respite, see summary table of military and Veterans programs at www.lifespanrespite.wildapricot.org/resources/Documents/Federal_Funding_Guide_2016/Matrix_FedFunding_Military.pdf.

STEP
5

How Do I Decide What's Right for Me?

Once you have decided to use respite care, you want to make sure the service you are considering is right for your situation. Unfortunately, in some areas there may only be one option for respite care. If you do have a choice of services, however, use the following tips when selecting what's right for you:

Before You Contact Potential Providers

- If you have feelings of guilt or anxiety about leaving your Veteran, speak to another family caregiver about their respite experiences. Using respite is like putting on an oxygen mask on the airplane before you assist someone else with their mask. Respite for you will mean that you will be better prepared to continue providing care.
- Call a family meeting to discuss the possibility of using respite services. If appropriate, be sure to include the Veteran in the discussion. Decide what would work best; in-home or out-of-home care, day care, or care in a facility.
- Discuss how often you would like to use the respite service.
- Confirm what each family member would need to make the most of respite care. Are there activities the Veteran would like to do while you are getting respite?
- Make a list of questions to ask potential providers (see ideas below).
- Create a checklist of important information you think the care provider needs to know about the medical, behavioral, and daily living (toileting, feeding, and mobility) needs of the person in care, including dietary, recreational and other preferences. (See **Step 8 Orienting Respite Providers** on page page 10.) Lots of guidebooks and templates exist to help you put this information

together. See the ABCs of Respite at www.archrespite.org/consumer-information.

- Consider strategies to increase safety and avoid theft, such as placing all valuables and medication in a safe. Will the respite provider be given a key or access to home security systems?

Contact Potential Providers

Once the family has had an initial discussion, and you have identified possible respite services or providers from the options discussed, ask each provider you are considering to send you a brochure in advance so you can get familiar with their services. Contact the potential providers along with your Veteran, when possible, and discuss your family's expectations and these questions:

- How are the workers selected and trained?
- Are background checks performed?
- Are respite workers licensed and bonded, if required?
- What tasks can be performed by the respite worker?
- Can the respite worker administer medications, assist with medical tasks or daily living needs, if necessary?
- Will the respite provider engage in or offer activities or companion services requested by the Veteran?
- What hours and days are services available?
- If the provider will be driving the care recipient, do they have a valid driver's license?
- What is the eligibility process?
- What are the fees and how are they paid?
- How are emergencies and problems handled?
- Are references available?

If you are considering respite services outside the home, request a tour for you and your loved one. When possible, visit the facility or program more

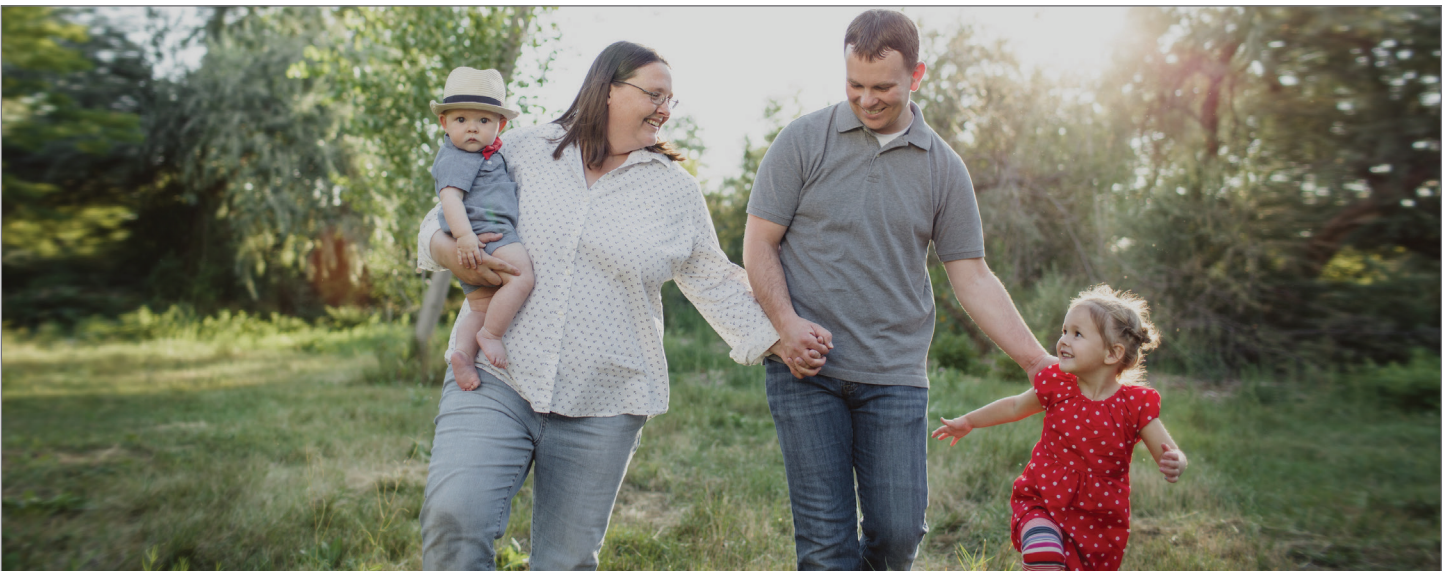


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than once and observe the engagement between participants and staff. Observe for cleanliness and the types of activities available. Are there opportunities for social engagement or other activities desired by the care recipient?

If you decide to hire a private independent respite worker who is not an employee of an agency, then the questions listed above become essential. In addition, it is even more important to check references, use telephone interviews to screen

providers, and conduct a background check for safety reasons. Although finding someone on your own is usually less expensive, it is more complicated. Remember, you may also be responsible for paying household employee taxes if you use one provider consistently. To find independent workers, start by asking family and friends, check with religious communities and online respite registries, and you may consider placing an ad in local newspapers or on Craig's List.



STEP
6

Preparing My Loved One for Respite

Respite provides a much needed break for both the caregiver and the care receiver. Some Veterans, however, may be resistant because they are uncomfortable in an unfamiliar environment or being with people who are considered “strangers.” Allowing someone new to help them may be outside of their comfort zone, and yours. Here are a few tips that may help:

- Introduce the idea of respite to your care recipient well in advance of when you might want to start using it. Planning is key! Set aside enough time to prepare your Veteran for the respite experience and enough time to plan for how it will occur.
- You, as the caregiver, have the primary responsibility for making the decision to access respite services. However, when it is possible, involving the care receiver in some aspects of respite service planning may help smooth the transition and assist in acceptance of respite care. Ways in which the care receiver might be involved could include choosing the location of service, activities, or time frames. Providing appealing respite options with desirable activities or social opportunities may increase the Veteran’s willingness to participate.
- When talking about the respite service, use positive language and show your excitement about the opportunity.
- Explain that you are feeling overwhelmed and would appreciate a little time to unwind.
- Try spending time with your loved one in the respite setting or with the respite provider to help them feel more comfortable.
- Have someone else who your care receiver respects explain how helpful respite will be for the family.

STEP
7

Planning to Make the Most of Respite

There are several ways you can make the most of your time away from caregiving.

- **Use Respite Early.** First, when possible, try to take a break on a regular basis beginning as soon as possible in your caregiving experience. Avoid waiting until you are overwhelmed and stressed.
- **Use Respite as Frequently as Possible.** By getting respite at least once a week, when possible, you can restore your balance and reduce stress.
- **Planning is Key.** You want to make sure your respite time is enjoyable. Find ways to use your time to reconnect with friends, exercise, participate in a hobby or get some much deserved rest. Plan what you will do during your respite times and resist waiting until the last minute to confirm your plans.
- **Focus on You.** Some respite initiatives might focus on activities specifically for you – through weekend retreats such as those offered by the Yellow Ribbon Fund or Hearts of Valor, respitality or get-aways, or caregiver education programs (see resource list at the end of the document). Remember, your goal with respite is to take care of yourself, while ensuring your loved one is safe and secure.





STEP
8

Orienting Respite Providers

As mentioned earlier, it will be helpful to create a checklist for the respite worker. Make it clear to the respite provider that you, as the caregiver, are the primary point of contact.

Checklist for the Respite Provider

- ✓ Your contact information
- ✓ The care receiver's likes and dislikes
- ✓ Information about special diets and medications
- ✓ An overview of a typical day in the life of the care receiver
- ✓ Tips for how to deal with any difficult behaviors exhibited by the care receiver

If the respite provider is qualified to perform medical tasks, administer medication, or assist with more complex activities of daily living, make sure you dedicate sufficient time before you leave to demonstrate correct and preferred approaches. You know your Veteran best. By sharing your expectations for how care is to be provided, you will help ensure the safety and well-being of your Veteran.

STEP
9

Find Out About Other Helpful Resources

Although being a caregiver is rewarding, it can also be challenging. Using respite services on a regular basis helps you be the best caregiver you can be. There are also a number of other types of services that can help. You will want to get all of the support and assistance that is available. Use the resource list below to find the most desirable, safe and appropriate respite options and other useful services:

HiddenHeroes.org: This website sponsored by the Elizabeth Dole Foundation provides a vetted directory of valuable resources to find organizations that help military caregivers and their families. www.hiddenheroes.org/

Additional Resources

General Respite Information

(What is respite, how to find, choose, plan and pay for it)

- **ARCH National Respite Network and Resource Center:**
 - ***The ABCs of Respite: A consumer guide for family caregivers*** www.archrespite.org/consumer-information
 - ***Time for Living and Caring: Making Respite Services Work for You*** www.archrespite.org/images/docs/Outside_Reports/Lund_TLCRespiteBrochure_2014.pdf

Caregiver Resources for the General Population

- **Caregiver Action Network (CAN)** is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge. www.caregiveraction.org
- **Family Care Navigator, Family Caregiver Alliance** lists caregiver resources and care recipient benefits



by state at www.caregiver.org/family-care-navigator

Specific to Military Caregivers and Military Families

- **ARCH National Respite Network and Resource Center Fact Sheet: Respite for Caregivers of Veterans** www.archrespite.org/images/docs/Factsheets/fs_63-Respite_Caregivers_Veterans.pdf
- **Caring for Military Families: The Elizabeth Dole Foundation** www.elizabethdolefoundation.org
- **Christopher and Dana Reeve Foundation, Paralysis Resource Center – Resources for Military/Veterans** www.christopherreeve.org/get-support/military-veterans-program-mvp
- **Department of Defense (DOD) Caregiver Resources** <http://warriorcare.dodlive.mil/caregiver-resources/>
- **Easterseals Military and Veterans Caregiver Training Services** www.easterseals.com/explore-resources/for-caregivers/military-veteran-caregivers.html

- **Hidden Heroes: America's Military Caregivers Report** www.elizabethdolefoundation.org/why-we-help/hidden-heroes-report
- **Military OneSource Exceptional Family Member Program Fact Sheets, Guide and Resources** on a variety of topics related to aging, disabilities, caregiving and family support at www.militaryonesource.mil/products
- **National Military Family Association** www.militaryfamily.org/info-resources/wounded-caregivers
- **Operation Family Caregiver, Rosalynn Carter Institute for Caregiving** coaches the families and friends of newly returning service members and veterans to manage difficult transitions. www.operationfamilycaregiver.org
- **Paralyzed Veterans of America (PVA)** www.pva.org/find-support/caregiver-support
- **PsychArmor Institute – Caregiver School** provides videos on what is respite and how to use it. www.caregiver.psycharmor.org

Hidden Heroes provides military and veteran caregivers with a directory of more than 200 carefully vetted resources and access to an online peer support community exclusively for caregivers. www.hiddenheroes.org/signup

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