



Community Caregiving Resources for Veterans and their Families

Numerous studies place the number of unpaid caregivers in America at roughly 40 million and the estimated annual amount of uncompensated care at \$470 billion. According to the Elizabeth Dole Foundation, there are 2.5 million veterans that use a caregiver and, of that number, 38,000 of these veterans are receiving services through the Department of Veterans Affairs (VA) Caregiver Program. Because of the strict eligibility criteria for the VA Caregiver Program, many veterans and their caregivers cannot avail themselves of its benefits and must turn to community programs and resources for support, information and assistance. This paper is intended to identify many of those caregiver community programs overseen by the federal government that may benefit all veterans and their families.

What Federal Agency is Responsible for Community Caregiver Programs?

The **Department of Health and Human Services (HHS) Administration on Community Living (ACL)** is the principal federal agency responsible for managing a variety of programs that offer assistance on health and wellness, protect rights and prevent abuse of vulnerable care recipients, support consumer control, and funding research into issues affecting caregivers. ACL also funds services and supports provided primarily by states and networks of community-based programs; and invests in training, education, research, and innovation. Information about the Administration on Community Living programs and councils that support those caring for older adults and people with disabilities can be found at www.acl.gov/programs/support-caregivers.

Where do I go for information at the local level?

Aging and Disability Networks are made up of local, state, and national organizations working to support older adults and people with disabilities. Some organizations focus on a particular type of disability, age group, or type of service, whereas others have a more comprehensive mission. These networks include Aging and Disability Resource Centers, Area Agencies on Aging, Centers for Independent Living, Protection and Advocacy Systems, and state units on aging. ACL helps support these networks and the programs and services they provide, information about which can be found at: <https://acl.gov/programs/aging-and-disability-networks>





What services are available for caregivers of older adults, children and people with disabilities?

The **National Family Caregiver Support Program (NFCSP)** provides grants to states and territories to fund various supports that help family and informal caregivers care for older adults in their homes for as long as possible. NFCSP grantees provide five types of services:

- information to caregivers about available services
- assistance to caregivers in gaining access to the services
- individual counseling, organization of support groups, and caregiver training
- respite care; and supplemental services, on a limited basis

As of the 2016 Reauthorization of the Older Americans Act, the following specific populations of caregivers are eligible to receive services through the NFCSP:

- 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
- Older relatives (not parents) age 55 and older providing care to children under the age of 18; and
- Older relatives, including parents, age 55 and older providing care to adults ages 18-59 with disabilities

To find out what services may be available in your state, contact your local Aging and Disability Network <https://acl.gov/programs/aging-and-disability-networks>.

Are there community respite services available?

Lifespan Respite Care programs are coordinated systems of community-based respite care services for family caregivers of children and adults of all ages with special needs. As of 2017, agencies in 37 states and the District of Columbia were operating respite care programs. These agencies are typically those administering Older Americans Act programs or those under Medicaid.

Today, grant recipients are focusing on integrating Lifespan Respite Care Programs into state systems of long-term services and supports. A recent round of grants requires states to provide gap-filling respite services to family caregivers, and to work with ACL to develop program performance and outcome measures.





Technical assistance (TA) is a key component of the Lifespan Respite Care program. Since 2009, ACL has funded the ARCH National Respite Network and Resource Center to provide TA to the Lifespan Respite Program grantees and the field.

ARCH's current TA activities focus on assisting states in the development of integrated respite programs across the lifespan; supporting the development of a framework to measure program performance and outcomes; and collecting, disseminating, and stimulating research in the field of respite and family caregiver support. For more information, visit the [ARCH National Respite Network and Resource Center](#).

The ARCH National Respite Network and Resource Center has a wide array of fact sheets tailored to caregivers' particular circumstances - <https://archrespite.org/consumer-information/family-caregiver-fact-sheets>. Among those fact sheets is one produced by the Elizabeth Dole Foundation - [https://archrespite.org/images/Caregiver Fact Sheets/Military Caregivers.pdf](https://archrespite.org/images/Caregiver_Fact_Sheets/Military_Caregivers.pdf).

Are there any programs available specifically for veteran caregivers that are ineligible for the VA Caregiver Program?

The Administration for Community Living (ACL) and Veterans Health Administration (VHA) established the **Veteran-Directed Care Program** (VDC) in 2008 as a collaboration to help veterans with disabilities of all ages and their families receive needed services in their own homes and communities. The VDC Program is targeted to veterans whose home care needs exceed the average number of hours generally available through the Homemaker/Home Health Aide (H/HHA) Program at a VA Medical Center (VAMC) or have difficulty with the traditional agency-based home care system, and who also desire to self-direct their services and supports.

All veterans enrolled in the VA health care system are eligible to participate in the VDC program when the veteran is "in need of nursing home care" and interested in self-directed care. The determination of whether a veteran qualifies for VDC is made by the VAMC based upon a predefined set of functional criteria and other social indicators.

This particular program combines the local experience of Aging & Disability Networks with the resources of VHA to provide veterans with additional opportunities to avoid nursing home placement and remain independent in the community. Under the VDC Program, veterans manage their own flexible spending budgets, decide for themselves what mix of goods and services can best meet their needs, hire and supervise their own workers, including family and friends, and purchase items or services that help them live independently. This model of service delivery is called "participant direction."

The VDC Program is offered through an Aging & Disability Network and provides veterans with a person-centered alternative to traditional home care services and





programs. This consumer-directed approach empowers the veteran to actively participate in making informed decisions about accessing health and long-term care options. Veterans in the VDC program then select the services and goods that will best meet their long-term care needs in order to prevent an avoidable hospital admission or premature nursing home placement. A veteran in the VDC Program is supported by: a VA program coordinator to oversee quality, satisfaction and service delivery; a counselor from an Area Agency on Aging (AAA), Aging & Disability Resource Center (ADRC) or Center for Independent Living to assist in finding/training workers and securing needed goods and services within the allocated budget; and, a financial management service to pay the bills, payroll taxes and ensure the integrity of the budget.

VAMCs refer eligible veterans to the Aging & Disability Network to enroll in the VDC Program. VAMCs authorize a flexible spending budget based on the veteran's assessed needs. The Aging & Disability Network works with the veteran to arrange and secure the needed goods and services within the budget and is also responsible for ensuring that the veteran's needs are met so that he or she can safely remain independent in the community.

As of April 2019, the Veteran Directed Care (VDC) Program is serving 2,166 Veterans across 37 States and the District of Columbia and Puerto Rico. At the same time, 86 Veterans Affairs Medical Centers (VAMCs) have partnered with Aging and Disability Network Agencies (ADNAs) including State Units on Aging (SUA), Aging & Disability Resource Centers (ADRCs), Area Agencies on Aging (AAAs) and Centers for Independent Living (CIL) to offer the program.

The VDC program is available through the Veteran's Health Administration's (VHA) Office of Geriatrics and Extended Care Services -

https://www.va.gov/GERIATRICAL/pages/Veteran-Directed_Care.asp. VAMCs are responsible for determining eligibility and making referrals to ADNAs for VDC. Please contact VAMCs for more information on availability of VDC locally and for questions regarding eligibility. You can find your nearest VA location at: <https://www.va.gov/directory/guide/home.asp>

The ADNAs listed at this link - <https://acl.gov/programs/veteran-directed-home-and-community-based-services/veteran-directed-home-community-based> -- have completed VA Readiness Reviews and have been approved as qualified providers for VDC. ADNAs are listed by state and VAMC that the ADNA will partner with to serve Veterans in VDC.

Where do I start to find out what is best for my family?





Finding the right services can be daunting for individuals and their family members. The current system involves numerous funding streams, and is administered by multiple federal, state, and local agencies. These agencies use complex, fragmented, and often duplicative intake, assessment, and eligibility processes.

Since 2014, ACL, the Centers for Medicare and Medicaid Services (CMS), and Veterans Health Administration (VHA) have collaborated in developing the **No Wrong Door (NWD) System** that aims to make it easier for all populations in need of long term services and supports to learn about and access the assistance they need. To date, 54 states and territories have been funded to implement NWD activities and 530 local NWD systems are in place nationwide to serve older adults and persons with disabilities and their families.

The NWD System initiative builds upon the Aging and Disability Resource Center (ADRC) program and CMS' Balancing Incentive Program No Wrong Door requirements that support state efforts to streamline access to long-term services and support (LTSS) options for older adults and individuals with disabilities. NWD Systems simplify access to LTSS, and are a key component of LTSS systems reform. To learn more about the No Wrong Door system go to <https://nwd.acl.gov>

Are there other resources my family might find useful?

Paralyzed Veterans of America - PVA's network of service offices stands ready to assist veterans and their caregivers with questions about VA benefits. To find your nearest national service officer, go to <https://pva.org/find-support/national-service-office/>.

Elizabeth Dole Foundation Hidden Heroes Caregiver Community -

www.HiddenHeroes.org - The Hidden Heroes Caregiver Community (HHCC) is an online support group that offers a positive place for military caregivers of all eras to connect with one another. Moderated by caregivers, the HHCC is a welcoming environment for military caregivers to share their stories, seek advice, and find commonality in the challenges they face. Military caregivers can register and join the HHCC through their website -HiddenHeroes.org.

AARP - www.AARP.org/caregiving - This resource page from AARP provides information about Medicaid and VA home and community based care programs, ways to get paid for caregiving, caregiving support communities and hotlines, legal information, what Medicare does and does not pay for

Caregiver Action Network - www.caregiveraction.org - CAN serves a broad spectrum of family caregivers ranging from the parents of children with significant health needs, to





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the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer's disease. CAN (the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

National Alliance for Caregiving - <https://www.caregiving.org/> - NAC conducts research, policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. In addition to national research and advocacy, NAC provides technical assistance to a national network of caregiving coalitions representing nearly 30 states and localities in the United States. Its resources web page - <https://www.caregiving.org/resources/> - contains links to government and nonprofit programs addressing elder care, financial management for caregivers, caregiving for patients with dementia, cancer, Alzheimer's and other specific conditions.

