Caregivers, Personal Care Attendants and Respite

Caregiving is not a role people usually choose. It seems to choose us, emerging from events and circumstances beyond our control.

This is a job that cannot be skirted and cannot always be delegated. It can be difficult, physically and emotionally. It can be time-consuming. While caring for
loved ones can be enormously satisfying, there are days, it seems, that offer little reward.

Caregivers, the men and women who care for family members and loved ones, deserve to be recognized and supported for the vital part they play in the lives of people with paralysis.

Caregivers may work in isolation from others in similar circumstances but they share much in common. It is important that caregivers connect with each other, to gain strength and to know that they are not alone.

It is essential that caregivers know about tools -- the homecare products and services -- that might make their jobs easier. It's also important that caregivers are aware of community and public resources that offer assistance.

Caregivers also need to know that support and respite systems exist to address the well-being and health of caregivers themselves.

The caregivers' links connect to several national organizations addressing the concerns of caregivers, including resources for hiring and managing personal care attendants.

Source: Christopher & Dana Reeve Foundation Paralysis Resource Center website
https://www.christopherreeve.org/living-with-paralysis/for-caregivers/caregivers

Web Sites

**Caregiver Action Network (formerly National Family Caregivers Association)**
http://caregiveraction.org
1150 Connecticut Ave, NW
Suite 501
Washington, DC 20036
Phone: 202-454-3970
General E-mail: info@caregiveraction.org
CAN educates, supports, empowers and speaks up for the more than 65 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. CAN reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well-being.

**The Family Caregiver Alliance**
http://www.caregiver.org/
101 Montgomery St., Suite 2150
San Francisco, CA 94103
Phone: 800-445.8106 (Toll-free)
E-mail: info@caregiver.org
FCA offers programs at national, state and local levels to support and sustain caregivers. FCA established the National Center on Caregiving to advance the development of high-quality, cost effective programs and policies for caregivers in every. FCA also oversees Link2Care, an Internet support and information system for clients of California's system of Caregiver Resource Centers and operates the Bay Area Caregiver Resource Center in the six-county San Francisco Bay Area.

**When Caregiving Ends (death of loved one)**
https://www.caregiver.org/resource/when-caregiving-ends/

**National Alliance for Caregiving (NAC)**
http://www.caregiving.org/
1730 Rhode Island Ave. NW, Suite 812
Washington, DC 20036
Phone: 202-918-1013
Email: info@caregiving.org
NAC is a non-profit coalition of national organizations focusing on issues of family caregiving. The Alliance was created to conduct research, do policy analysis, develop national programs, increase public awareness of family caregiving issues, work to strengthen state and local caregiving coalitions, and represent the US caregiving community internationally.

**Well Spouse Association (WSA)**
http://www.wellspouse.org/
63 West Main Street, Suite H
Freehold, NJ 07728
Phone: 800-838-0879 (Toll-free)
E-mail: info@wellspouse.org
The WSA advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse/partner. The organization educates health care professionals and the general public about the special challenges and unique issues of "well” spouses, facilitates a mentor program, and publishes a newsletter (*Mainstay*) and e-newsletter (*Member Minute*), among other activities. Peer to peer support is offered through a national network of support groups and an on-line chat forum.

**AARP: Caregiving**
http://www.aarp.org/relationships/caregiving/
AARP offers articles, tools, work sheets and tips on how to plan, prepare and succeed as a caregiver.

**AARP and National Alliance for Caregiving: Caregiving in the U.S. 2015 report**

**AARP and United Hospital Fund’s Report: Home Alone—Family Caregivers Providing Complex Chronic Care**
Administration for Community Living: National Family Caregiver Support Program (NFCSP)
https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program
330 C St. SW
Washington, DC 20201
Phone: 202-401-4634
The NFCSP provides grants to states and territories to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.

American Association of Caregiving Youth
https://www.aacy.org/
6401 Congress Ave., Suite 200
Boca Raton, FL 33487
Phone: 561-391-7401
Email: info@aacy.org
The mission of AACY is to increase awareness and provide support services for youth caregivers and their families.

American Psychological Association: State and National Resource Locators and Tools to Coordinate Caregiver Support

American Red Cross: Caregiving
http://www.redcross.org/take-a-class/program-highlights/nurse-assistant-training#family caregiving course
The American Red Cross offers a Family Caregiving Program that has been designed to: teach skills for caring for the elderly, chronically ill and disabled at home; help community organizations provide services that benefit seniors; and prepare families to take on the responsibility and challenges of caring for a loved one at home. The program consists of 9 one-hour modules on various topics. Participants can take any number of the modules.

Caregiver Media Group
http://www.caregiver.com
3920 Riverland Rd.
Fort Lauderdale, FL 33312
Phone: 954-893-0550
Email: info@caregiver.com
This site provides information, support and guidance for family and professional caregivers through topic-specific newsletters, online discussion lists, chat rooms
and an online store. Caregiver Media Group also publishes *Today’s Caregiver Magazine*.

**Caring Connections**
http://www.caringinfo.org  
https://www.nhpco.org/patients-and-caregivers/  
Alexandria, VA  
Phone: 703-837-1500  
E-mail: caringinfo@nhpco.org  
Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life. The program provides free resources and information to help people make decisions about end-of-life care and services before a crisis.

**Caregiving.com**
http://www.caregiving.com/  
3323 W. Addison, MB6  
Chicago, IL 60618  
Phone: 773-343-6341  
This site features the blogs of family caregivers, weekly words of comforts, free webinars and online support groups.

**The Center for WorkLife Law**
https://worklifelaw.org/  
UC Hastings College of the Law  
200 McAllister Street  
San Francisco, CA 94102  
Phone: 415-565-4640  
Email: hotline@worklifelaw.org  
A non-profit research and advocacy organization that seeks to eliminate discrimination against caregivers in the workplace.

**Leeza’s Care Connection**
https://leezascareconnection.org/  
501 S Buena Vista St  
Burbank, CA 91505  
Phone: 818-847-3686  
Email: info@leezascareconnection.org  
201 St. Andrews Rd.  
Columbia, SC 29210  
Phone: 803-888-7525  
Leeza’s Care Connection is dedicated to connecting family caregivers with each other and with the information and support they need while they are walking the caregiving path. They offer virtual connection, wellness activities and educational workshops to caregivers.
Making the Move to Managing Your Own Personal Assistance Services: A Toolkit for Youth with Disabilities Transitioning to Adulthood

MedlinePlus: Caregivers
www.medlineplus.gov
Type caregivers in search box. This page has general information on caregiving as well as links to other resources related to coping and specific conditions.

National Caregivers Library
http://www.caregiverslibrary.org
901 Moorefield Park Drive, Suite 100
Richmond, VA 23236
Phone: 804-327-1111
Email: jodi@caregiverslibrary.com
The National Caregivers Library from FamilyCare America has articles, forms, checklists, and links to other resources on topics such as caregiving basics, self-care, care facilities, end-of-life issues, finances, and government resources.

National Volunteer Caregiving Network
www.nvcnetwork.org
1765 Goodyear Ave., Suite 204
Ventura, CA 93003
Phone: 512-582-2197
A non-profit organization whose mission is to support volunteer caregiving organizations.

Next Step in Care
http://www.nextstepincare.org/
This site provides information and advice to family caregivers and health care professionals to plan smooth and safe transitions between care settings, for example from hospital to rehabilitation center to home.

No Barriers USA
https://nobARRIERsusA.org/
605 South College Ave, #101
Fort Collins, CO 80524
Phone: 970-484-3633
Provides services to caregivers. The Arch Foundation merged into No Barriers in 2019.

Northwest Regional Spinal Cord Injury System: Personal Caregivers – Tips, Tricks and Tales from Individuals with Spinal Cord Injury
http://sci.washington.edu/info/forums/reports/caregivers.asp
University of Washington
Rehabilitation Medicine
Box 356490
Seattle, WA 98195
At an April 8, 2008 forum, three individuals with longstanding quadriplegia described their experiences and shared tips for finding, hiring and managing personal caregivers. These presentations were followed by a brief talk by a University of Washington rehabilitation psychologist about maintaining personal boundaries when working with a personal caregiver. The presentations can be read as a report or watched as a 63-minute streaming video.

Open Caregiving: Caregiving Glossary
https://www.opencaregiving.com/glossary

Road Scholar Caregiver Grant
www.RoadScholar.org/caregivergrant
Phone: 617-457-5429
Email: scholarships@roadscholar.org
The Road Scholar is a non-profit organization which offers unpaid family caregivers a chance to receive a scholarship of up to $1,300 to take part in a Road Scholar educational travel program. The grant is for caregivers who are 50 and older and live in the United States. Please contact them for any other eligibility requirements.

Rosalynn Carter Institute for Caregiving (RCI)
www.RosalynnCarter.org
Georgia Southwestern State University
800 GSW Drive
Americus, GA 31709-4379
Phone: 229-928-1234
Through research, education and training, the RCI promotes the mental health and well-being of caregivers, delineates effective caregiving practices, builds public awareness of caregiving needs, advances public and social policies that enhance caring communities.

Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill
http://www.sharethecare.org
ShareTheCaregiving™, Inc. seeks to improve the "quality of life" of persons who are seriously ill, disabled, or experiencing the challenges of aging, and to reduce stress, depression, isolation and economic hardship often suffered by their family caregivers. The organization is introducing a new paradigm in which ordinary people pool their efforts to help ease the burden on family caregivers and help those without family nearby.
Shepherd’s Centers of America (SCA)
http://www.shepherdcenters.org/
5559 NW Barry Rd., #333
Kansas City, MO 64154
Phone: 816-960-2022
Email: staff@shepherdcenters.org
An interfaith, not-for-profit organization that coordinates nearly 100 independent Shepherd's Centers across the U.S to help older adults remain independent in their own living situation.

Women’s Health.gov: Caregiver Stress
https://www.womenshealth.gov/a-z-topics/caregiver-stress
200 Independence Ave SW
Washington, DC 20201
Phone: 800-994-9662
This fact sheet is designed to help women recognize if caregiver stress is a problem and has recommendations for obtaining help and relieving stress.

Women’s Institute for a Secure Retirement (WISER): Financial Steps for Caregivers – What You Need to Know About Protecting Your Money and Retirement
This guide is intended to help women understand the financial consequences of caregiving and plan for a more secure future.

Craig Hospital: Caregivers and Personal Assistants Resources
https://craighospital.org/resources/topics/caregivers-and-alternative-therapy
3425 S Clarkson St.
Englewood, CO 80113
Phone: 303-784-8000
Email: support@craighospital.org

Respite Care – General Information

Respite is short-term breaks from caregiving for family caregivers. Respite can happen in the home, in a group setting, or can result when the person living with a disability takes part in activities that don’t require the presence of the family caregiver.

ARCH National Respite Network and Resource Center
http://www.archrespite.org
The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.
ARCH: Fact Sheets
http://www.archrespite.org/productspublications/arch-fact-sheets
This page has fact sheets on a variety of topics related to respite for caregivers of children and adults. Most are aimed at people managing respite programs.

ARCH: Lifespan Respite Task Force
The Lifespan Respite Task Force, established in 2000, is a coalition of over 100 national and state organizations which serves to develop and promote a national respite policy. The Task Force was a major force in passing the Lifespan Respite Act of 2006.

ARCH: Lifespan Respite Care Act 2006
Text of the law authorizing $289 million over five years for state grants to develop Lifespan Respite Programs to help families access quality, affordable respite care. Lifespan respite programs are defined in the Act as “coordinated systems of accessible, community-based respite care services for family caregivers of children and adults with special needs.”

Caring Communities
http://www.caringcommunities.org/
1341 W. Liberty Rd.
Sykesville, Maryland 21784
Phone: 410-549-5707
E-mail: info@caringcommunities.org
Caring Communities offers respite care training for adults and teens in Maryland.

TimeBanks USA
www.timebanks.org
5500 39th St. NW
Washington, DC 20015
Phone: 202-686-5200
Offers membership in time banks in which one can perform a service and bank the hours donated in order to get a different service in return. Respite for caregiving could be earned in this way.

Locating Respite Care

ARCH: National Respite Locator
http://archrespite.org/respitelocator
The National Respite Locator Service helps parents, family caregivers, and professionals find respite services in their state and local area to match their specific needs.

ARCH: State Respite Coalitions
http://archrespite.org/state-respite-coalitions
This page lists contact information for state respite coalitions. These coalitions are grassroots membership organizations composed of public and private organizations; family caregivers; and respite, social service and health care providers. Most often their activities are focused on advocacy, networking, and public education.

Additional organizations are listed below by state.

Alaska

Assisted Care Services
http://www.assistedcareak.com/
P.O. Box 221876
Anchorage, AK 99522
Phone: 907-929-2828, 866-516-2687 (Toll-free)
E-mail: info@assistedcareak.com

Florida

Florida Respite Coalition
http://archrespite.org/respite-locator-service-state-information/141-florida-info
E-mail: Contact@FloridaRespite.Org

Hawaii

Catholic Charities Hawai‘i (CCH)
http://www.catholiccharitieshawaii.org/
1822 Ke‘eauumoku St.
Honolulu, HI 96822
Phone: 808-521-4357
Email: info@catholiccharitieshawaii.org
CCH provides respite for caregivers of seniors (60 years and older) and linkages to private hire providers. Limited financial support for respite services is available.

Illinois

Illinois Respite Coalition
http://www.illinoisrespitecoalition.org/
2650 S. Taylorville Rd.
Decatur, IL 62521
Phone: 773-205-3627
Email: galvanr@maryvilleacademy.org
The Illinois Respite Coalition is an organization of caregivers and respite providers dedicated to advocating support for families by ensuring access to quality respite services for residents of Illinois.

Kentucky
Kentucky Caregiver Support Services
https://chfs.ky.gov/agencies/dail/Pages/caregiversupport.aspx
275 E. Main St.
Frankfort, KY 40621
Phone: 502-564-6930 x3505
Email: CHFS.Listens@ky.gov

Michigan

Judson Center
http://www.judsoncenter.org/
3031 Northwestern Highway, Suite 100
Farmington Hills, MI 48334
Judson Center provides respite care in three locations: Lahser Respite Home in Beverly Hills, Macomb Respite Home in New Baltimore, and Rose F. Kennedy Respite Center in Westland.

LAP Respite Center
http://www.helpinghandsrespite.care
201 Hillside Court
East Lansing, MI 48823
Phone: 517-372-6671
LAP Respite Center provides lifespan respite services for families who care for children or adults with disabilities, chronic illness, or age-related conditions. Respite services are available to families living within Ingham, Eaton and Clinton counties.

Minnesota

LSS Caregiver Support and Respite Services
http://www.lssmn.org/respite/
2485 Como Ave.
St Paul, MN 55108
Phone: 651-642-5990
Phone: 800-582-5260 (Toll-free)
Email: caregiver@lssmn.org
LSS (Lutheran Social Services) offers short-term, non-medical respite care for people 60 and older.

Minnesota Department of Health: Respite Care
http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_002203
Phone: 651-431-2000
Email: DHSinfo@state.mn.us

Mississippi
Mississippi Department of Human Services, Division of Aging & Adult Services  
[Website](http://www.mdhs.ms.gov/adults-seniors)  
200 South Lamar St.  
Jackson, MS 39201  
Phone: 601-359-4929  
The In-Home Services Program provides respite care in some areas.

Missouri

St. Louis ARC  
[Website](http://www.slarc.org/)  
1177 N. Warson Road  
St. Louis, MO 63132  
Phone: 314-569-2211

New Jersey

Family Support Center of New Jersey  
[Website](http://www.fscnj.org/)  
1 AAA Dr., Suite 203  
Trenton, NJ 08691  
Toll-free: 800-336-5843

Family Support Coalition of New Jersey  
[Website](http://www.familysupportcoalition.org/)  
985 Livingston Ave.  
North Brunswick, NJ 08902  
E-mail: fscnj.info@gmail.com

New Mexico

New Mexico Department of Health: Respite Services Program  
[Website](https://nmhealth.org/about/ddsd/pgsv/sgf/respite/)  
1190 S. St. Francis Drive  
Santa Fe, NM 87502  
Phone: 505-827-2613

Ohio

Ohio Family Care Association  
[Website](http://www.ofcaonline.org)  
303 E. Broad St.  
Columbus, OH 43215  
Phone: 614-222-2712  
E-mail: office@ofcaonline.org
Pennsylvania

Special Kids Network System of Care
https://www.health.pa.gov/topics/programs/Special%20Kids%20Network/Pages/Special%20Kids%20Network.aspx
Phone: 800-986-4550

South Carolina

South Carolina Respite Coalition
www.screspitecoalition.org
PO Box 493
Columbia, SC 29202
Phone: 803-935-5027
Email: screspitecoalition@yahoo.com

Vermont

Vermont Department of Disabilities, Aging & Independent Living
http://dail.vermont.gov/
HS 2 South, 280 State Dr.
Waterbury, VT 05671-1601
Phone: 802-241-2401

Washington

Senior Services
http://soundgenerations.org
Lillian Rice Building
2208 Second Avenue, Suite 100
Seattle, WA 98121
Phone: 206-448-5757
E-mail: info@soundgenerations.org

Wyoming

Wyoming Department of Health: State Respite Program
401 Hathaway Bldg.
Cheyenne, WY 82002
Phone: 307-777-7175
Toll-free: 800-442-2766
Email: wyaging@wyo.gov
The State Respite Program provides respite care to caregivers for children under age 21 with a severe, chronic disability which is attributable to a mental, emotional or physical impairment or a combination of impairments.
Personal Care Attendants

Center for Personal Assistance Services (CPAS)
http://clpc.ucsf.edu/about-community-living-policy-center
Department of Social and Behavioral Sciences
School of Nursing
University of California
3333 California Street, Suite 340
San Francisco, CA 94118-0612
Phone: 866-727-9577 (Toll-free)
CPAS provides research, training, dissemination and technical assistance on issues of personal assistance services (PAS) in the United States.

Centers for Medicare and Medicaid: Direct Service Workforce Initiative
Direct service workers perform personal care for individuals.

Christopher & Dana Reeve Foundation: PCA blog series:
Parting with Your PCA 6/24/19 https://www.christopherreeve.org/blog/daily-dose/parting-with-your-personal-care-attendant

Independent Living Institute: Consumer Directed Personal Assistance Guide
http://www.independentliving.org/docs6/conceptsmanual.html#anchor46
This site has detailed tips for hiring, training and working with a personal assistant.

New Mobility: The Business of Managing Your PCAs
Article from August 2017 issue.

Origin
http://www.origincare.com/
7.0.6. Cameron House
White Cross
Lancaster LA1 4XQ
UK
Phone: 01524 34100
E-mail: info@origincare.com
Origin is an experienced, specialist care agency providing, one-to-one, 24 hour, live-in care services for people with spinal cord injuries. The company is owned and managed by a man who is spinal cord injured.

**Employment as a Caregiver**

Those seeking employment as a caregiver may want to check their local offices of:

Independent Living Centers
Visiting Nurse associations
ARCH Respite

**Support and Support Groups**

**Barren Heights Christian Retreat Center**
http://www.barrenheights.com/
11420 Watterson Ct. #800
Louisville, KY 40299
Phone: 502-327-9495
Barren Heights provides free weekend retreats to families of children with physical and/or developmental disabilities from May through October.

**Caregiver.com: Support Group Finder by State**
http://www.caregiver.com/regionalresources/index.htm

**Well Spouse Association: WSA Support Groups and State Contacts**
http://www.wellspouse.org
63 W Main St Suite H
Freehold, NJ 07728
Phone: 732-577-8899
This page lists contact information for support groups for spousal caregivers.

**Caring Bridge**
http://www.caringbridge.org
2750 Blue Water Road Suite 275
Eagan, MN 55121
Phone: 651-452-7940
Caring Bridge offers free private websites where people can blog about an individual's health status. Friends and family can post guestbook messages.

**Lotsa Helping Hands**
http://www.lotsahelpinghands.com
118N. Peoria St, 3rd Floor
Chicago, IL 60607
This site offers free private community pages to organize volunteers in helping an individual with health care or other needs.
Chat Rooms/Online Discussion Groups

Caregiver Media Group
http://www.caregiver.com
This site has online discussion lists and chat rooms.

Well Spouse Association (WSA)
http://www.wellspouse.org/
Phone: 800-838-0879
The WSA offers an on-line chat forum.

Professional Travel Companions

Medical Travel, Inc.
www.medicaltravel.org
6307 Hansel Ave.
Orlando, FL 32809
Phone: 407-438-8010
Toll-free: 866-322-4400
E-Mail: ada@medicaltravel.org
Medical Travel provides registered occupational, physical and respiratory therapists, RN's and LPN's, and experienced travel companions to accompany clients around the world on local and long-distance trips by air, sea or train.

Print Magazines

Mainstay
http://www.wellspouse.org/
A quarterly newsletter written by and for members of the Well Spouse Association.

Today's Caregiver
https://caregiver.com/magazine
Published 6 times a year by Caregiver Media Group.

E-mail or Online Newsletters

TAKE CARE! Self Care for the Family Caregiver
www.caregiveraction.org
A monthly e-newsletter is available to members of the Caregiver Action Network (CAN).

Caregiver.com Newsletter
http://www.caregiver.com/caregiver_newsletter/index.htm
Free newsletter sent once a week via email.

Family Caregiver Alliance (FCA): Newsletters
FCA publishes four free e-newsletters covering all aspects of long-term family caregiving. They are: The Newsletter of the Technical Assistance Centers with
information for the aging and lifespan respite networks about best practices, key research findings, and policy trends; Caregiving PolicyDigest, a twice-monthly briefing on current federal and state legislation, new programs and funding initiatives for long-term caregiving; Connections, focusing on issues and information important to caregivers; and Newslink, a publication exclusively for Link2Care members.

**Streaming Videos**

**VideoCaregiving**
http://www.videocaregiving.org/
Click on the Caregiving tab to see some stroke and general caregiving videos.

**E-books**

**Shepherd Center’s electronic book “How to Successfully Hire and Manage a Personal Care Assistant for People with Spinal Cord Injury”**
Can be downloaded to Mac or iOS devices.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.

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