

Caregivers, Personal Care Attendants and Respite



Figure 1:Photo Courtesy of Permobil.

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 loved one) of 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

http://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html

AARP and United Hospital Fund's Report: Home Alone—Family Caregivers **Providing Complex Chronic Care**

https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

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

http://www.apa.org/pi/about/publications/caregivers/resources/locators.aspx

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: <u>info@caregiver.com</u>

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

https://pueblo.gpo.gov/CAARNG/ODEP/PDF/ODEP051.pdf

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 III

http://www.sharethecare.org

c/o National Center for Civic Innovation 121 Avenue of the Americas, 6th floor

New York, NY 10013 Phone: 212-991-9688

E-mail: info@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

https://www.wiserwomen.org/wp-content/uploads/2020/09/financial-steps-for-caregivers-budget-worksheet-9.2020.pdf

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

http://www.archrespite.org/national-respite-coalition/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

http://www.archrespite.org/images/docs/Lifespan_Respite_Act_2006.pdf

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 Hawaiii (CCH)

http://www.catholiccharitieshawaii.org/

1822 Ke'eaumoku 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 espite 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: <u>caregiver@lssmn.org</u>

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_CONVERS ION&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

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

http://www.slarc.org/ 1177 N. Warson Road St. Louis, MO 63132 Phone: 314-569-2211

New Jersey

Family Support Center of New Jersey

http://www.fscnj.org/ 1 AAA Dr., Suite203 Trenton, NJ 08691 Toll-free: 800-336-5843

Family Support Coalition of New Jersey

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

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

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: <u>screspitecoalition@yahoo.com</u>

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

https://health.wyo.gov/aging/communityliving/older-americans-act-programs/nfcp/

401 Hathaway Bldg. Cheyenne, WY 82002 Phone: 307-777-7175 Toll-free: 800-442-2766

Toll-free: 800-442-2766 Email: <u>wyaging@wyo.gov</u>

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

https://www.medicaid.gov/medicaid/long-term-services-supports/workforce-initiative/index.html#:~:text=Workforce%20Initiative%20As%20the%20primary%2 Ofunder%20of%20long-

<u>term,the%20paid%20and%20informal%20direct%20service%20community%20workforce.</u>

Direct service workers perform personal care for individuals.

Christopher & Dana Reeve Foundation: PCA blog series:

Selecting and Hiring a PCA 6/4/19

https://www.christopherreeve.org/blog/daily-dose/selecting-and-hiring-apca

Managing a PCA 6/11/19

https://www.christopherreeve.org/blog/daily-dose/blog-two-managing-a-personal-care-attendant-pca

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

http://www.newmobility.com/2017/08/managing-personal-care-assistants/ 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 questbook 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

https://www.caregiver.org/about-fca/news-press/connections-newsletter/

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 *News*link, 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"

https://itunes.apple.com/us/book/how-to-successfully-hire-manage/id756884980?mt=11&ign-mpt=uo%3D4

Can be downloaded to Mac or iOS devices.

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