



Caregivers, Personal Care Attendants and Respite

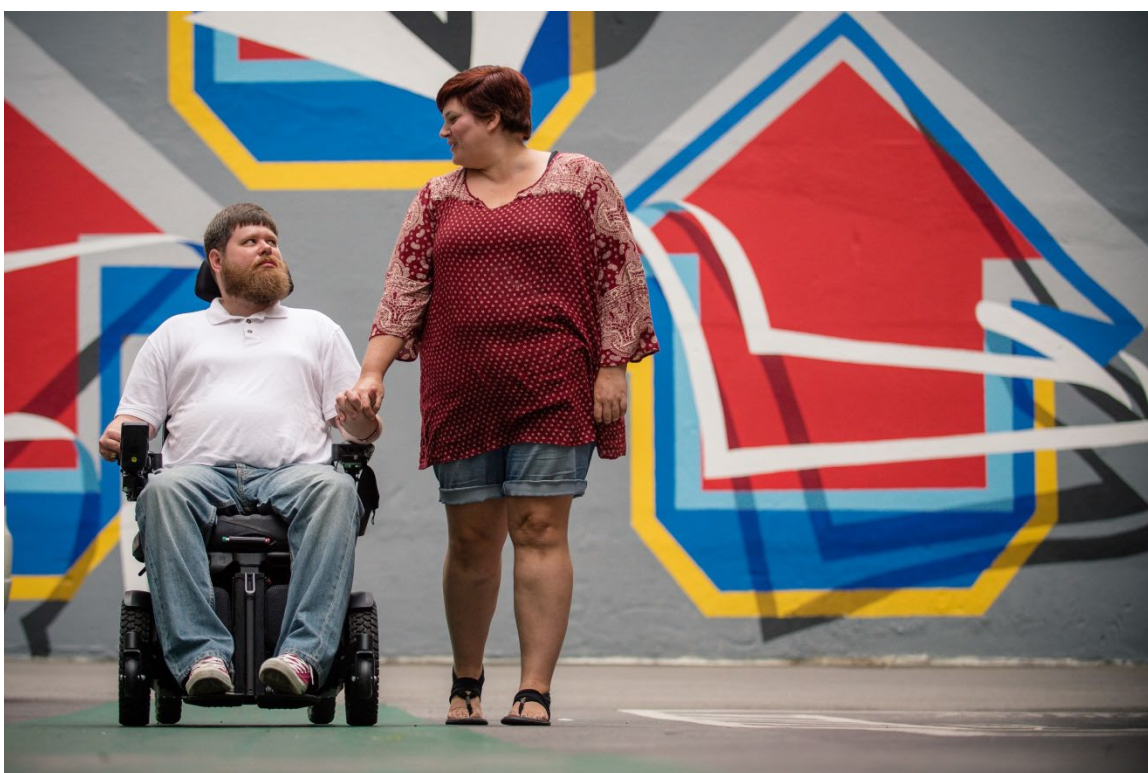


Figure 1: Photo Courtesy of Permobil.

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: 855-227-3640

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. CAN offers a **Caregiver Help Desk** to answer questions from caregivers from 8 am to 7 pm. Please call 855-227-3640 to reach it.

The Family Caregiver Alliance

<http://www.caregiver.org/>

235 Montgomery Street, Suite 930

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: 732-577-8899

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.

Aging Forward (formerly Shepherd's Centers of America)

<https://aging-forward.org/>

820 Armour Rd.

Kansas City, MO 64116

Phone: 816-960-2022

An interfaith, not-for-profit organization that coordinates 55 independent centers across the U.S to help older adults remain independent in their own living situation.

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](http://www.redcross.org/take-a-class/program-highlights/nurse-assistant-training#family%20caregiving%20course)

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>

1900 West Oakland Park Blvd.

Oakland Park, FL 33310

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>

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 Volunteer Caregiving Network

www.nvcnetwork.org

1765 Goodyear Ave., Suite 204

Ventura, CA 93003

Phone: 512-582-2197

Email : info@nvcnetwork.org

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/>

301 Boardwalk Dr.

Box 270637

Fort Collins, CO 80527

Email: info@nobarriersusa.org

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

PO Box 56033

Boston, MA 02205

Phone: 800-454-5768

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>

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 Center: Rebuilding Together—A Guide for Caregivers

<https://www.shepherd.org/about/publications>

Shepherd offers an electronic booklet about spinal cord injury for caregivers as well as one about acquired brain injury for caregivers.

Women's Health.gov: Caregiver Stress

<https://www.womenshealth.gov/a-z-topics/caregiver-stress>

1101 Wootton Parkway,
Rockville, MD 20852

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

Email: rehab@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.

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

Email: info@timebanks.org

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://archrespice.org/respice-locator-service-state-information/141-florida-info>
E-mail: Contact@FloridaRespice.Org

Hawaii

Catholic Charities Hawai'i (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.illinoisrespitcoalition.org/>
555 Skokie Blvd., Suite 500
Northbrook, IL 60062
Phone: 866-455-7377
Email: ilrespitcoalition@gmail.com

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: 502-564-5497
Toll-free : 800-372-2973
Email: CHFS.Listens@ky.gov

Michigan

Judson Center

<http://www.judsoncenter.org/>
3031 Northwestern Highway, Suite 100
Farmington Hills, MI 48334

Phone: 248-549-4339

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.

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: 651-297-3862

Toll-free: 800-657-3672

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: 601-359-4500

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

Ohio

Ohio Family Care Association

<http://www.ofcaonline.org>

2931 Indianola Ave.

Columbus, OH 43202

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: info@screspitecoalition.org

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/>

2300 Capitol Ave., 4th Floor

Cheyenne, WY 82002

Phone: 307-777-7995

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

<https://www.medicaid.gov/medicaid/long-term-services-supports/workforce-initiative/index.html#:~:text=Workforce%20Initiative%20As%20the%20primary%20funder%20of%20long-term,the%20paid%20and%20informal%20direct%20service%20community%20workforce.>

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-a-pca>

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/conceptsmannual.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.

Caring Bridge

<http://www.caringbridge.org>

2750 Blue Water Road Suite 275

Eagan, MN 55121

Phone: 651-789-2300

Email: customercare@caringbridge.org

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, 2nd Floor

Chicago, IL 60607

Email: info@lotsahelpinghands.com

This site offers free private community pages to organize volunteers in helping an individual with health care or other needs.

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.

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.

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 *Newslink*, a publication exclusively for Link2Care members.

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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