



The following excerpt has been taken from the Christopher & Dana Reeve Foundation Paralysis Resource Center website.

<http://www.paralysis.org/site/c.erJMJUOxFmH/b.1297513/k.1C01/Caregivers.htm>

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.

Web Sites

www.caregiver.com

Caregiver Media Group

Provides information, support and guidance for family and professional caregivers. Publishes Today's Caregiver Magazine and offers a web site with topic-specific newsletters, online discussion lists, chat rooms and an online store.

<http://www.thefamilycaregiver.org> or www.nfcacares.org

The National Family Caregivers Association (NFCA)

NFCA is a grass roots organization created to educate, support, empower and speak up for the millions of Americans who care for chronically ill, aged or disabled loved ones. NFCA is the only constituency organization that reaches across the boundaries of different diagnoses, different relationships and different life stages to address the common needs and concerns of all family caregivers. More than one quarter (26.6%) of the adult population has provided care to a family member or friend during the past year. Based on current census data, that translates into more than 54 million people.

www.familycaregiving101.org

Family Caregiving: It's Not All Up to You

NFCA and the National Alliance for Caregiving launched a public education campaign to give information and support to caregivers.

www.wellspouse.org/

Well Spouse Association

A national, not for profit membership organization that gives support to wives, husbands, and partners of the chronically ill and/or disabled. Through information and support groups, the organization address issues common to family caregivers: anger, guilt, fear, isolation, grief, and financial threat.

<http://groups.yahoo.com/group/scic/>

Spinal Cord Injury Caregivers

Yahoo Internet Forum is a place to share information and to support other caregivers who are caring for people with SCI.

www.shepherdcenters.org/

Shepherd's Centers of America (SCA)

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.

www.caregiving.com/

The Center for Family Caregivers

The Center for Family Caregivers and Denise Brown operate Tad Publishing Co., which produces books, newsletters and other materials for families and health care professionals who care for chronically ill or disabled family members.

www.caregiverslibrary.org

National Caregivers Library

www.caregiver.org/

The Family Caregiver Alliance

The lead agency in California's system of Caregiver Resource Centers and operates the National Center on Caregiving to advance the development of support programs for family caregivers in every state. For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating brain disorders that strike adults.

<http://www.strengthforcaring.com/>

The Caregiver Initiative is a project of the Johnson & Johnson Consumer Products Company and works with many caregiving organizations to help family caregivers provide care to their loved ones and reduce their own stress. The Caregiver Initiative consists of a comprehensive website, information on caregiver needs, and training materials for family caregivers. The website, Strength for Caring, is an online resource and community for family caregivers.

www.caregiversadvisorypanel.com/

The Caregivers Advisory Panel

Collects confidential information on the opinions and needs of family caregivers to help health care products manufacturers and service providers to create innovative products, services, programs and support for America's caregiving families.

www.caringroad.com

CaringRoad.com is dedicated to helping family caregivers obtain information, locate services and find support so they can make informed decisions about the care of their loved ones. An online community of family caregivers.

Phone: 609-773-0773

info@caringroad.com

<http://www.strengthforcaring.com/>

Strength for Caring is a site for family caregivers from Johnson & Johnson.

www.sharethecare.org

Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill
Sharethecaregiving, Inc.

646-467-8097

<http://www.redcross.org/portal/site/en/menuitem.d229a5f06620c6052b1ecfbf43181aa0/?vgnextoid=58d2914124dbe110VgnVCM10000089f0870aRCRD&vgnnextchannel=bf970c45f663b110VgnVCM10000089f0870aRCRD>

American Red Cross Family Caregiving Program

Offers 9 courses on caregiving. Each is a one-hour class.

<http://www.aarp.org/families/caregiving/>

The **American Association of Retired Persons** offers various articles on caregiving.

www.4woman.gov/faq/caregiver.htm?src=ng

The **National Women's Health Information Center** has information on caregiver stress.

<http://www.craighospital.org/sci/mets/caregiving.asp>

Craig Hospital

Article on family caregiving specific to spinal cord injury.

<http://images.main.uab.edu/spinalcord/pdf/files/17care.pdf>

University of Alabama-Birmingham

Infosheet #17 Caregivers for SCI

<http://www.spinalcord.ar.gov/attendant.html>

Arkansas Spinal Cord Commission: Attendant Care

www.nlm.nih.gov/medlineplus/caregivers.html

MedlinePlus: Caregivers

<http://www.als-mda.org/publications/alscare/>

Muscular Dystrophy Association

Online book on ALS caregiving.

<http://www.caregiving.org/data/milesaway.pdf>

Miles Away: The MetLife Study of Long Distance Caregiving

<http://www.aging-parents-and-elder-care.com/>

Aging Parents and Elder Care

Articles, comprehensive checklists, links to key resources, a support group.

http://www.wiserwomen.org/portal/index.php?option=com_content&task=blogsection&id=2&Itemid=29

Women's Institute for a Secure Retirement (WISER)

Booklet "Financial Steps for Caregivers: What You Need to Know About Money and Retirement"

<http://www.cmrg.com/>

Case Management Resource Guide online

Lists various types of services including case managers, home health care agencies, nursing agencies, etc.

www.worklifelaw.org

Center for WorkLife Law at University of California's Hastings College of the Law. A non-profit research and advocacy organization that seeks to eliminate discrimination against caregivers in the workplace.

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

Next Step in Care provides info and advice to family caregivers and health care professionals to plan smooth and safe transitions from hospital to rehab center to home.

Caring Connections: A program of the National Hospice and Palliative Care Organization is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.

www.caringinfo.org

Phone: 800-658-8898

1700 Diagonal Rd., Suite 625

Alexandria, VA 22314

<http://www.medicare.gov/caregivers/>

Medicare: Caregiver Information

Help with navigating Medicare and its services

www.MyChildWithoutLimits.org

My Child Without Limits from UCP

Respite Care

www.archrespite.org

<http://chtop.org/ARCH/State-Respite-Coalitions.html>

State Respite Coalitions

Provides helpline and referrals to other respite services in the respective state.

www.alabamarespite.org/

Alabama Lifespan Respite Resource Network

Toll Free: (866) 737-8252

California Respite Services Association

Family Support Services of the Bay Area

401 Grand Avenue, Suite 500

Oakland, California 94610

jlevin@fssba-oak.org

Colorado Respite Coalition

Scott Bates

Colorado Children's Trust Fund, Family Resource Centers CO Department of Public Health and Environment

4300 Cherry Creek Drive South

Denver, Colorado 80246
(303) 692-2941
scott.bates@state.co.us

<http://www.dmr.state.ct.us/srrespiteneews.htm>

Connecticut Lifespan Respite Coalition

Supports the development of coordinated respite services for caregivers and providers of respite for individuals of all ages throughout the state.

Florida Respite Coalition

Toll Free: 1-866-FL-RELIEF

Georgia Lifespan Respite Coalition

Family Support Program Director
Georgia Community Support and Solutions
1945 Cliff Valley Way, Suite 220
Atlanta, Georgia 30329
(404) 634-4222 Ext. 242
Fax (404) 634-1324

Illinois Lifespan Respite Coalition

Nia Comprehensive Center
1808 South State Street
Chicago, Illinois 60616
(312) 949-9412
Fax (312)949-9415
Nia_1808@msn.com

www.crisisnursery.net

Illinois Crisis Nursery Coalition

1309 W. Hill Street
Urbana, IL 61801
(217) 337-2731

www.irccc.com

Iowa Respite and Crisis Care Coalition

3821 71st Street, Suite A
Urbandale, IA 50322
(515) 309-0858
1-877-255-3140

<http://www.rockoinc.org/about.html>

Respite Outreach Care for Kids Organization, Inc. (ROCKO)

1705 S. Lantern Lane Ct.

Andover, Kansas 67002
(316) 218-9363

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

Louisiana Federation of Families for Children's Mental Health

5627 Superior Dr., Suite A-2
Baton Rouge, Louisiana 70816
(318) 227-2796
Fax (318) 227-2793

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

Maryland Respite Care Coalition, Inc

Provides a forum to share information, experiences, and training to create effective programs to assist and empower families with respite requirements.

Alidz Khachaturian
451 Khachaturian Drive #119-166
Rockville, Maryland 20850
(240)453-9585
alidz_khachaturian@idt.net

State of Maryland Department of Human Resources - Office of Adult Services

Dorinda Adams
Program Specialist
311 West Saratoga Street
Baltimore, Maryland 21201-3521
(410) 767-7323
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Dadams@dhr.state.md.us

Massachusetts Respite Coalition

Emily Davidson
126 Mount Auburn Street
Cambridge, Massachusetts 02138
(617) 355-4658
emily.davidson@tch.harvard.edu

Michigan Respite Coalition

Doug Cunningham, Chair
Community Respite Centers, Inc.
P.O. Box 507
Jackson, MI 49204-0507
Phone(517) 788-7533
Fax (517) 796-5981
doug@communityrespite.com

Crisis Nurseries of Minnesota, Inc.

Haley Morgan
CAP Agency Crisis Nursery - Scott/Carver Counties
712 Canterbury Road South
Shakopee, Minnesota 55379
(952) 402-9832
Fax (952) 402-9815
Haley.Morgan@CAPAgency.org

St. Louis ARC

Mark Keeley
President
1816 Lackland Hill Parkway, Suite 200
St. Louis, Missouri 63146
(314) 569-0247
Fax (314) 569-0632
mkeeley@slarc.org

Montana Respite Coalition

Vicki Clear
Lifespan Respite Specialist
Developmental Educational Assistance Program
2200 Box Elder
Miles City, Montana 59301
(406) 234-6034
Fax (406) 232-7018
vclear@deapmt.org

Nebraska Respite Coalition

Chris Stewart
Eastern Area for the Nebraska Respite Network across the Lifespan
(402) 996-8444
Fax (402) 420-2585
respitcenter@yahoo.com
<http://www.answers4families.org/family/info/familyrespit.html>
Coordinates respite providers, programs, and consumers across the state of Nebraska. The toll-free number is: 1 866-RESPITE (737-7483)

Nevada Respite Coalition

Scherrie Adams-Ambre
Give me a Break
P.O. Box 620721
Las Vegas, Nevada 89162
(866) 486-2275
givemeabreakinc@aol.com

Family Support Coalition of New Jersey

John Rubis
Vice President
P.O. Box 1052
Mt. Laurel, New Jersey 08054
1-800-372-6510
jrubis@snip.net

Family Support Center of New Jersey

429 Riverview Plaza
Trenton, New Jersey 08611
(609) 392-5621
<http://www.familysupportnj.com/>

North Carolina Respite Coalition

Phyllis Stephenson
Chair Person
Easter Seals UCP of North Carolina
P.O. Box 165
Gibsonville, North Carolina 27249
(336) 449-7904
Fax (336) 449-7934
pstephenson@nc.eastersealsucp.com

State Point of Contact

Ohio Family Care Association
Dot Erickson, Director
P.O. Box 82185
Columbus, Ohio 43202
(614) 268-7776
Fax (614) 262-7004
OFCA@aol.com
www.ofcaonline.org

Oklahoma Respite Resource Network

Rose Ann Percival
Program Manager
OASIS/OUHSC
P.O. Box 26901
Oklahoma City, Oklahoma 73125
(405) 522-0600
Fax (405) 522-1687
RoseAnn.Percival@okdhs.org

Oklahoma Respite Resource Network

Madalyn McCollom
OASIS Project Director
P.O. Box 26901
Oklahoma City, Oklahoma 73125
1-800-426-2747 or (405) 271-6302
Fax (405) 271-6305
madalyn-mccollom@ouhsc.edu

Oregon Lifespan Respite Care Program

Lee Girard
State Unit on Aging/Lifespan Respite
DHS-Seniors & People with disabilities
(503) 947-1199
Lee.A.Girard@state.or.us
http://www.oregon.gov/DHS/spd/caregiving/ls_respite.shtml

Pennsylvania Respite Coalition

Watson Insitute
MaryJo Alimena Caruso
Carebreak Coordinator
301 Camp Meeting Road
Sewickley, Pennsylvania 15143
(412) 749-2863
Fax (412) 749-2891
maryjo@thewatsoninstitute.org

The Special Kids Network

Larry Klinger, Jr.
Director of Community System Development
1705 Maple Street, Suite 204
Home Stead, Pennsylvania 15120

South Carolina Respite Coalition

Susan Carlton
Executive Director
P.O. Box 493
Columbia, South Carolina 29202
(803) 799-9819
Fax (803)935-5250
screspitcoalition@yahoo.com

South Dakota Respite Coalition

Kathy Olson
Department of Human Services
Hillsview Plaza,

E. Hwy. 34, c/o 500 East Capitol
Pierre, SD 57501-5070
Kathy.Olson@state.sd.us
<http://dhs.sd.gov/dd/respite/index.aspx>

Tennessee Respite Coalition

Louise Barnes
1120 Lipscombe Drive
Nashville, Tennessee 37204
(615) 532-6727
Louise.Barnes@state.tn.us
<http://www.tnrespite.org/>

Utah Association of Family Support Centers

Sue Hoffman
Child and Family Support Center
380 West 1400 North
Logan, Utah 84341
(435) 752-8880
suehoff@xmission.com

State Point of Contact
Monica Uhl

Virginia Respite Resource Project
Partnership for People with Disabilities
Virginia Commonwealth University
P.O. Box 843020
Richmond, Virginia 23284-3020
(804) 828-8587
Fax (804) 828-0042
muhl@mail1.vcu.edu

Respite and Crisis Care Coalition of Washington State

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Arc of King County
10550 Lake City Way NE, Suite A
Seattle, Washington 98117-4419
(206) 364-4645 x122
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Senior Services, Inc.

Sally Friedman
Co-chair
1601 2nd Avenue, Suite 800
Seattle, Washington 98101

(206) 727-6260
(206) 448-3110
sallyf@seniorservices.org

Respite Care Association of Wisconsin

Jim Schroeder
Executive Director
6320 Monona Street --Suite 407
Monona, WI 53716
(608) 222-2033, or (608) 222-2034
jschroeder@respitecarewi.org
www.respitecarewi.org

<http://www.archrespite.org/index.htm>

The **ARCH National Respite Network** includes the National Respite Locator, a service to help caregivers and professionals locate respite services in their community and the National Respite Coalition, a service that advocates for respite care services and programs at the national, state, and local levels.

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

National Respite Coalition's Respite Locator

National Respite Coalition and the National Respite Locator Service help parents, caregivers, and professionals find respite services in their state and local area.

<http://www.archrespite.org/NRC.htm>

Lifespan Respite Care Act 2006

This new law authorizes \$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." Text of the law is available here.

<http://www.autism-pdd.net/respite.html>

Autism PDD Support Network: Respite Care

Includes a checklist of questions to ask when contacting respite agencies.

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

Caring Communities

A group that is chartered to train respite care providers and to provide respite-related family support services in most counties in the state of Maryland.

<http://www.familycaregiving101.org/help/respite.cfm>

Family Caregiving 101

A list of respite resources: national organizations, programs, and referral services.

Fact sheets and resources from ARCH National Resource Center for Respite and Crisis Care Services on Respite Care for Children:

- Respite Care: Q&A

www.thearc.org/NetCommunity/Document.doc?&id=160

- Understanding the Temporary Child Care Act

<http://www.archrespite.org/archfs31.htm>

- Respite Care for Children Who are Medically Fragile

<http://www.archrespite.org/archfs11.htm>

- Respite Care for Children with Developmental and/or Physical Disabilities: A Parent's Perspective

<http://www.archrespite.org/archfs4.htm>

Personal Care Attendants

<http://www.pascenter.org/home/index.php>

Center for Personal Assistance Services

The Center for Personal Assistance Services provides research, training, dissemination and technical assistance on issues of personal assistance services (PAS) in the United States.

www.craighospital.org/sci/mets/careassisthire.asp

Personal Care Attendants

Information from Craig Hospital on finding, hiring and keeping reliable PCAs. From the home page, click on Health and Wellness under the Spinal Cord Injury section, then click on Educational Brochures. Scroll to the Caregiving section.

www.tbi-sci.org/pdf/pas.pdf

Hiring and Management of Personal Care Assistants for Individuals with SCI

A downloadable, 26-page booklet from the SCI Project at Santa Clara Valley Medical Center. Covers everything from locating and hiring, to training personal assistants. Includes forms, checklists and resources. (In pdf format).

www.dswresourcecenter.org

National Direct Service Workforce Resource Center from the Centers for Medicare & Medicaid Services

1-877-822-2647

supports efforts to improve recruitment and retention of direct service workers who help people with disabilities and older adults to live independently and with dignity.

www.umshp.org

www.infouse.com/pas

InfoUse: Working Together Personal Assistance Training and You

www.independentliving.org/docs6/conceptsmannual.html#anchor46

Independent Living Institute's Consumer Directed Personal Assistance Guide

http://www.cashandcounseling.org/about/index_html

Cash & Counseling

The Cash & Counseling approach provides a flexible monthly allowance to recipients of Medicaid personal care services or home and community based services.

Origin

<http://www.origincare.com/>

Provides live-in caregivers for people who are spinal cord injured. Company is in the U.K. The company is owned and managed by a man who is spinal cord injured.

Barren Heights Retreat

3109 Brownsboro Vista

Louisville, KY 40242

Phone: 502-327-9495

Email: Joebobrose@bellsouth.net

A non-profit organization that provides weekend retreats for family caregivers of a physically disabled child at no cost to the family. This is a Christian charity that focuses on strengthening family identity and Christian community.

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 Groups

www.caregiver.com

<http://www.caregiver.com/regionalresources/index.htm>

Caregiver.com Support Group Finder by State

http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx

Administration on Aging's National Family Caregiver Support Program

The Caregiver Resource Room is where families, caregivers, and professionals can find information about The National Family Caregiver Support Program, support and assistance, and providing services to caregivers.

www.wellspouse.org

<http://www.wellspouse.org/wsa-support-groups-and-state-contacts/sgl-contacts/>

Well Spouse Foundation's Support Groups by State

For spousal caregivers.

www.carepages.com or use the link to CarePages at www.paralysis.org

CarePages are private web sites that bring together patients and families to offer strength, support and encouragement when it's needed most. Families can post entries on how their family member is doing.

www.caringbridge.org

Caring Bridge is a free site that updates a network of friends and family about an individual's health status. People can post guestbook messages.

www.lotsahelpinghands.com

Lotsa Helping Hands is a free online service to organize volunteers in helping an individual with health care or other needs. Shows a calendar so people can see when help is needed for that individual.

Chat Rooms/Online Discussion Groups

<http://groups.yahoo.com/group/scic/>

Yahoo's Spinal Cord Injury Caregivers Forum

Yahoo Internet Forum is a place to share information and to support other caregivers who are caring for people with SCI.

Delphi Forum: CareShare

<http://forums.delphiforums.com/careshare/start>

An internet forum where caregivers can ask, share, encourage and vent.

Print Magazines

Families of Loved Ones (FOLO)

www.familiesoflovedones.com

Available in print or downloadable from website.

Mainstay—a quarterly newsletter from The Well Spouse Association.

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

Take Care!—a quarterly newsletter from the National Family Caregivers Association

www.nfcacares.org

Today's Caregiver—Published 6 times a year by Caregiver Media Group, see

www.caregiver.com to subscribe

Email or Online Newsletters

Caregiver.com Newsletter—free newsletter sent once a week via email. Go to www.caregiver.com to subscribe.

Family Caregiver Alliance Update—free newsletter readable at site: http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=346
Also see their Fact Sheets readable online.

Professional Travel Companions

Medical Travel, Inc.

5184 Majorca Club Dr., Boca Raton, FL 33486

1-800-778-7953

www.medicaltravel.org/all/companions.htm

E-Mail: ada@medicaltravel.org

Nurse Transport

1-800-484-8682, PIN#1058

900 41st St. West, Bradenton, FL 34205

Streaming Videos—watch at these websites

<http://besmartbewell.com/caregiving/index.htm>

Caregiving: A Matter of Balance

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

VideoCaregiving

Click on Caregiving tab to see some stroke and general caregiving videos

The following books and videos are available for free loan from the PRC library. For more information, please see www.paralysis.org and click the Lending Library tab.

Books

- **American Medical Association: A Guide to Home Caregiving.** Perry, Angela, editor. Canada: John Wiley & Sons, 2001.
- Banister, Katie Rodriguez. **The Personal Care Attendant Guide: The Art of Finding, Keeping or Being One.** New York: Demos, 2007.

- Barg, Gary. **The Fearless Caregiver: How to get the best care for your loved one and still have a life of your own.** Sterling, VA: Capital Books, 2001.
- Burack-Weiss, Ann. **The Caregiver's Tale: Loss and Renewal in Memoirs of Family Life.** New York: Columbia University Press, 2006.
- Capossela, Cappy and Sheila Warnock. **Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill.** New York: Fireside, 2004. Revised and Updated edition.
- Canfield, Jack et al. **Chicken Soup for the Caregivers Soul: Stories to inspire caregivers in the home, the community and the world.** Deerfield Beach, FL: Health Communication, 2004.
- Cardenas, David. **Earth Lessons for Care Givers Vol. 1: Case Studies to Train and Support Those Caring for the Terminally Ill.** San Francisco: FMA Books, 2002.
- **A Celebration of Caregiving: Portraits & Stories.** Milwaukee: Independence First, 2007.
- Cohen, Marion Deutsche. **Dirty Details: The Days and Nights of a Well Spouse.** Philadelphia: Temple University Press, 1996. (multiple sclerosis)
- **The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers.** Carol Levine and Thomas H. Murray, editors. Baltimore: Johns Hopkins Press, 2007.
- Decker, Joanne. **Making the Moments Count: Leisure Activities for Caregiving Relationships.** Baltimore, MA: The Johns Hopkins University Press, 1997.
- DeGraff, Alfred H. **Caregivers and Personal Assistants: How to Find, Hire and Manage the People who Help You (or Your Loved One!).** 3rd ed. Fort Collins, CO: Saratoga Access Publications Inc., 2002.
- Drattell, Alan. **The Other Victim: How Caregivers Survive a Loved One's Chronic Illness.** Santa Ana, CA: Seven Locks Press, 1996. (multiple sclerosis caregivers' stories)
- Halper, June et al. **Nursing Practice in Multiple Sclerosis: A Core Curriculum.** New York: Demos Medical Publishing, 2006. 2nd ed.
- Holicky, Richard. **Taking Care of Yourself While Providing Care: A Guide for those who assist and care for their spouses, children, parents, and other**

- loved ones who have spinal cord injuries.** Englewood, CO: Craig Hospital, 2000. Call 303-789-8202 to order for \$5.00.
- Hutchison, Joyce. **May I Walk You Home? : Courage and comfort for caregivers of the very ill.** Notre Dame, IN: Ave Maria Press, 1999.
 - Ilardo, Joseph and Carole R. Rothman. **I'll Take Care of You: A Practical Guide for Family Caregivers.** Oakland, CA: New Harbinger Publications, 1999.
 - Jacobs, Barry J. **The Emotional Survival Guide for Caregivers.** New York: Guilford Press, 2006.
 - Johnson, Anne M. and Ruth Rejnis. **The Cost of Caring: Money Skills for Caregivers.** New York: John Wiley & Sons, 1998.
 - Kleiman, Berenice. **Lessons Learned: Stroke Recovery from a Caregiver's Perspective.** Cleveland, Ohio: Cleveland Clinic Press, 2007.
 - Kramer, Betty J. and Edward H. Thompson Jr. **Men As Caregivers.** Amherst, NY: Prometheus Books, 2005.
 - Langshur, Eric and Sharon. **We Carry Each Other: Getting Through Life's Toughest Times.** San Francisco: Conari Press, 2007. A book on caregiving from the founders of CarePages.
 - LaRocca, Nicholas and Rosalind Kalb. **Multiple Sclerosis: Understanding the Cognitive Challenges.** New York: Demos Medical Publishing, 2006.
 - Leahy, William. **Caregiving At Home.** Albuquerque, NM: Hartman Publishing, 2005.
 - Leal, Carmen. **The Twenty-Third Psalm for Caregivers.** Chattanooga, TN: AMG Publishers, 2004.
 - Levine, Carol. **Always On Call: When Illness Always Turns Families On Call into Caregivers.** Nashville, TN. Vanderbilt University Press, 2004.
 - Lynn, Dorree and Florence Isaacs. **When the Man You Love is Ill: Doing Your Best for Your Partner Without Losing Yourself.** New York: Marlowe & Co., 2007.
 - Mandel, Debbie. **Changing Habits: The Caregiver's Total Workout.** Totowa, NJ: Resurrection Press, 2005.
 - Marella, Dee. **Who Cares: A loving guide for caregivers.** Sanford, FL: DC Press, 2002.

- Marriott, Hugh. **The Selfish Pig's Guide to Caring**. London: Time Warner Books, 2003.
- McCallion, Philip, PhD, ACSW and Matthew Janicki, PhD. **Grandparents as Carers of Children with Disabilities: Facing the Challenges**. Binghamton, NY: Haworth Press, 2000.
- McLeod, Beth Witrogen. **And Thou Shalt Honor: The Caregiver's Companion**. Rodale Press, 2002.
- McLeod, Beth Witrogen. **Caregiving: The Spiritual Journey of Love, Loss, and Renewal**. New York: John Wiley & Sons, 1999.
- Meyer, Maria M. and Paula Derr. **The Comfort of Home: A Complete Guide for Caregivers**. Portland, OR: CareTrust Publications, 2007. 3rd ed.
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Provides instructions on procedures such as urinary catheterization and tracheotomy care.

Videos

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Caregiver Wellness. Healing Arts Communications, 1996. DVD 32 minutes.

Caregiving: With Eyes Open Coping With Death. Princeton, NJ: Films for the Humanities & Sciences, 2000. 26 minutes

Caregiving: Wheelchair. Cicero, NY: Program Development Associates, 1996. 24 minutes.

Caring for the Caregiver. Program Development Associates. 28 minutes. Can be purchased from PDA at 1-800-543-2119.

This video helps the caregiver so that they don't neglect their own health.

Christopher & Dana Reeve Foundation's streaming video on Caregiving

View for free at www.paralysis.org Click See All Videos at top right, click on Paralysis Resource Center tab on top right

Consumer Direction in Personal Assistance: Consumer Direction – What is it?

Cicero, NY: Program Development Associates, 2002.

Includes a Learning Guide booklet.

Consumer Direction in Personal Assistance: Health and Safety. Cicero, NY:

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Consumer Direction in Personal Assistance: Rights and Responsibilities. Cicero,

NY: Programs Development Associates, 2002.

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The Educated Caregiver: A Comprehensive Guide for Caregivers and Their Families. LifeView Resources. A three video series: Coping Skills, Hands-On Skills, and Essential Knowledge. Available from Caregiver Media Group at www.caregiver.com Covers everything from coping with the emotional challenges of caregiving to patient transfers and preventing bedsores.

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How to Help Someone Who Uses a Wheelchair Without Hurting Yourself.

(Caregiving Series Vol. 2) Healing Arts Communications. 24 minutes. Can be purchased from Program Development Associates 1-800-543-2119.

How to Use a Mechanical Lift. Home Care Companion, Caregiving Series. Healing Arts Communications, 2006. DVD (23 minutes)

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Safe and Courteous Wheelchair Handling: Helping People Using a Wheelchair.

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