



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](http://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](http://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](http://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/](http://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/](http://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/](http://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](http://www.caregiverslibrary.org)

**National Caregivers Library**

[www.caregiver.org/](http://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/](http://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](http://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](mailto:info@caringroad.com)

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

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

[www.sharethecare.org](http://www.sharethecare.org)

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

646-467-8097

[www.redcross.org/services/hss/care/family.html](http://www.redcross.org/services/hss/care/family.html)

**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](http://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/pdffiles/17care.pdf>

**University of Alabama-Birmingham**

Infosheet #17 Caregivers for SCI

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

**Arkansas Spinal Cord Commission: Attendant Care**

[www.nlm.nih.gov/medlineplus/caregivers.html](http://www.nlm.nih.gov/medlineplus/caregivers.html)

**MedlinePlus: Caregivers**

<http://www.mdausa.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.aoa.gov/prof/aoaprogram/caregiver/WISER.pdf>

**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](http://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.

**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](http://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

**Respite Care**

[www.archrespice.org](http://www.archrespice.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/](http://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](mailto: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](mailto:scott.bates@state.co.us)

<http://www.dmr.state.ct.us/srrespiteneeds.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.

<http://www.floridarespice.org/search/frcsearch.asp>

**Florida Respite Coalition**

An online provider directory to give relief to family members and caregivers. There is also a toll-free number to contact the FRC directly: 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](mailto:Nia_1808@msn.com)

[www.crisisnursery.net](http://www.crisisnursery.net)

**Illinois Crisis Nursery Coalition**

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

[www.irccc.com](http://www.irccc.com)

**Iowa Respite and Crisis Care Coalition**

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

[www.rockoinc.org](http://www.rockoinc.org)

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

1705 S. Lantern Lane Ct.  
Andover, Kansas 67002  
(316) 218-9363

[www.laffcmh.com](http://www.laffcmh.com)

**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](mailto: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

Fax (410) 333-0256

[Dadams@dhr.state.md.us](mailto:Dadams@dhr.state.md.us)

**Massachusetts Respite Coalition**

Emily Davidson1

126 Mount Auburn Street

Cambridge, Massachusetts 02138

(617) 355-4658

[emily.davidson@tch.harvard.edu](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](http://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](mailto: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](mailto: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](mailto:Lee.A.Girard@state.or.us)

[http://www.oregon.gov/DHS/spd/caregiving/ls\\_respitem.html](http://www.oregon.gov/DHS/spd/caregiving/ls_respitem.html)

**Pennsylvania Respite Coalition**

Watson Institute

MaryJo Alimena Caruso

Carebreak Coordinator

301 Camp Meeting Road

Sewickley, Pennsylvania 15143

(412) 749-2863

Fax (412) 749-2891

[maryjoa@thewatsoninstitute.org](mailto:maryjoa@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](mailto: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](mailto:Kathy.Olson@state.sd.us)

<http://dhs.sd.gov/dd/respitem/index.aspx>

**Tennessee Respite Coalition**

Louise Barnes

1120 Lipscombe Drive

Nashville, Tennessee 37204

(615) 532-6727

[Louise.Barnes@state.tn.us](mailto:Louise.Barnes@state.tn.us)

<http://www.tnrespitem.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](mailto: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](mailto:muhl@mail1.vcu.edu)

**Respite and Crisis Care Coalition of Washington State**

Laurie Holscher  
Arc of King County  
10550 Lake City Way NE, Suite A  
Seattle, Washington 98117-4419  
(206) 364-4645 x122  
Fax (206) 364-8140  
[lhseattle@aol.com](mailto:lhseattle@aol.com)

**Senior Services, Inc.**

Sally Friedman  
Co-chair  
1601 2nd Avenue, Suite 800  
Seattle, Washington 98101  
(206) 727-6260  
(206) 448-3110  
[sallyf@seniorservices.org](mailto: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@respitcarewi.org](mailto:jschroeder@respitcarewi.org)  
[www.respitcarewi.org](http://www.respitcarewi.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](http://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](http://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](http://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](http://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.

<http://www.umshp.org/hp/resources/sci/scimanuals.htm#pasmanual>

**Missouri Model Spinal Cord Injury System's Enhancing Independence: A Personal Attendant Training Manual**  
(pdf file) downloadable for free

[www.infouse.com/pas](http://www.infouse.com/pas)

### **InfoUse: Working Together Personal Assistance Training and You**

[www.independentliving.org/docs6/conceptsmannual.html#anchor46](http://www.independentliving.org/docs6/conceptsmannual.html#anchor46)

### **Independent Living Institute's Consumer Directed Personal Assistance Guide**

[http://www.cashandcounseling.org/about/index\\_html](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](mailto: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)

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

**Caregiver.com** Support Group Finder by State

<http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.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)

[http://www.wellspouse.org/index.php?option=com\\_content&task=category&sectionid=8&id=28&Itemid=54](http://www.wellspouse.org/index.php?option=com_content&task=category&sectionid=8&id=28&Itemid=54)

### **Well Spouse Foundation's Support Groups by State**

For spousal caregivers.

[www.carepages.com](http://www.carepages.com) or use the link to CarePages at [www.paralysis.org](http://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.

## 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](http://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](http://www.nfcacares.org)

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

[www.caregiver.com](http://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](http://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](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](http://www.medicaltravel.org/all/companions.htm)

E-Mail: [ada@medicaltravel.org](mailto:ada@medicaltravel.org)

### **Nurse Transport**

1-800-484-8682, PIN#1058

900 41<sup>st</sup> St. West, Bradenton, FL 34205

The following books and videos are available for free loan from the PRC library. For more information, please see [www.paralysis.org](http://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.
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## 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 and Dana Reeve Foundation's streaming video on Caregiving**

View for free at [www.paralysis.org](http://www.paralysis.org)

<http://www.paralysis.org/site/c.erJMJUOxFmH/b.2627993/k.1D2E/Caregivers.htm>

**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: Program Development Associates, 2002.  
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**Consumer Direction in Personal Assistance: Communication.** Cicero, NY: Program Development Associates, 2002.  
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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](http://www.caregiver.com)  
Covers everything from coping with the emotional challenges of caregiving to patient transfers and preventing bedsores.

**Family Caregivers (The Doctor is In series).** Princeton, NJ: Films for the Humanities and Sciences, 1992. (30 minutes)

**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)

**In Spirit.** Sherborn, MA: Aquarius Healthcare Videos, 2001. (28 minutes)  
Aneice Taylor became paralyzed from the neck down in 1982 when a mudslide destroyed her home. She founded IN SPIRIT to help quads stay home with attendant care.

**Respite Care: Caring for the Caregiver.** Sherborn, MA: Aquarius Healthcare Videos, 2003. (25 minutes)

**Safe and Courteous Wheelchair Handling: Helping People Using a Wheelchair.** Sherborn, Mass.: Aquarius, 2006. DVD. (14 minutes)

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