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For many individuals with SCI, part of coming to terms with the spinal cord injury is accepting that as a result of physical limitations, there is now a need to rely on someone else to fulfill some of your needs. Personal assistant services can include a variety of activities which range from assistance with grocery shopping and meal preparation to bathing, bowel and bladder care. The Personal Care Assistant (PCA) is the person who assists the individual with SCI with his or her self-care activities. The PCA is also referred to as an “attendant” or “caregiver” whether the care is being provided by a family member, friend or hired employee.

Included in this chapter are resources to assist you with finding, hiring and managing a PCA. A good first step in finding a PCA is to contact your local Independent Living Center (ILC). Attendant care is one of the key services ILCs are funded to provide. Most ILCs keep a listing of potential attendants that may or may not have been first screened by the staff, and some offer classes to train the person with SCI who may need assistance with the hiring and management process. Classes may even be offered for the prospective attendant, who may not be familiar with the issues involved in caring for an individual with SCI. For the ILC nearest you, refer to Chapter 13.

In-Home Support Services (IHSS)

408/928-3737

591 N. King Rd.

San Jose, CA 95133

- County social services agency
- Based on SSI qualifications
- Personal Care Assistant (PCA) funding. This office only supplies the money to those who qualify to pay the PCA’s wages. Finding and supervising the PCA is the responsibility of the individual with SCI

Independent Living Research Utilization (ILRU)

713/520-0232

TIRR

1333 Moursund

Houston, TX 77019

- Research and Training Center in Independent Living, which has books and manuals available on attendant care

3. Attendant Care Resources

Silicon Valley Independent Living Center

408/894-9041

FAX: 408/894-9050

2306 Zanker Rd.

San Jose, CA 95131

Website: <www.svilc.org>

Silicon Valley Independent Living Center - Gilroy

408/847-1805

7415 Egleberry Street, Suite C

Gilroy, CA 95020

- Personal Care Assistant recruitment and referral, training in the management of PCAs
- Advocacy and legal services
- Information and referral regarding available and accessible housing

ON-LINE RESOURCES

In-Home Support Services Website

Website: <www.calhomecare.org>

- This website tracks current advocacy efforts, legislative initiatives and events to improve home care worker pay and benefits

The DRM WebWatcher

Disability Resources Monthly

Website: <www.disabilityresources.org/PCA.html>

- Online links to many SCI related websites with information on personal care assistants

University of Alabama at Birmingham

Spinal Cord Injury Information Network

Website: <www.spinalcord.uab.edu>

- An excellent website where 18 Fact Sheets covering various aspects of spinal cord injury are available free of charge. Select P and choose "Personal Attendant Services" for a variety of on-line documents and other resources, some of which are available in Spanish

BOOKS AND PAMPHLETS

Attendant Care Services - Fact Sheet #7

Arkansas Spinal Cord Commission

501/324-9624

1120 Marshall Street, Suite 207

Little Rock, AR 72202

3. Attendant Care Resources

Avoiding Attendants from Hell:

A Practical Guide to Finding, Hiring and Keeping Personal Care Attendants (1998)

Science and Humanities Press

636/394-4950

FAX: 636/394-1381

P.O. Box 7151

Chesterfield, MO 63006-7151

E-mail: publisher@sciencehumanitiespress.com

Website: <www.sciencehumanitiespress.com>

A Checklist for Evaluating Personal Care Assistant Services (1993)

Center on Human Policy

Syracuse University

200 Huntington Hall

Syracuse, NY 13244-2340

Enhancing Independence: A Personal Care Attendant Training Manual

Shellie Nazarus, Information Specialist

Missouri Model Spinal Cord Injury System

Howard A. Rusk Rehabilitation Center

573/882-3341

One Hospital Drive, DC046.00

Columbia, MO 65212

Getting from Here to There - A Manual on Personal Assistance (1996)

Catherine D. Ludlum

A. J. Pappanikou Center

860/486-5035

249 Glenbrook Rd., U-64

Storrs, CT 06269-2064

Hiring and Management of Personal Care Assistants for Individuals with Spinal Cord Injury (1999)

Debra L. Burdsall, MPH, OTR

Rehabilitation Research Center for TBI and SCI

Santa Clara Valley Medical Center

800/352-1956 x24

408/295-9896 x24

FAX: 408/295-9913

950 S. Bascom Ave., Suite 2011

San Jose, CA 95128

Available online at <www.tbi-sci.org>

3. Attendant Care Resources

Hiring Home Health Caregivers (1995)

Helen Susik
Impact Publishers
805/543-5911
P.O. Box 1094
San Luis Obispo, CA 93406

Personal Assistance Service Guide (1998)

Utah Assistive Technology Program
Center for Persons with Disabilities
435/797-1991
FAX: 435/797-2355
6588 Old Main Hill
Logan, UT 84322-6855
E-mail: mhammond@cc.usu.edu
Website: <www.uatp.usu.edu>

Personal Assistance Training Manual (1997)

Shepherd Center
404/350-7473
2020 Peachtree Rd. NW
Atlanta, GA 30309

Personal Care Assistants: How to Find, Hire and Keep Them (1995)

Available in English and Spanish
Research Department
RRTC on Aging with a Spinal Cord Injury
Craig Hospital
800/573-4228
303/789-8202
3425 S. Clarkson Street
Englewood, CO 80110

Personal Care Assistants - SCI Information Sheet #6

RRTC Training Office - Room 506
University of Alabama at Birmingham
205/934-3283
Spain Rehabilitation Center
1717 6th Ave., South
Birmingham, AL 35233-7330

3. Attendant Care Resources

Preventing Secondary Medical Complications:

A Guide for Personal Assistance to People with Spinal Cord Injury (1992)

UAB - Spain Rehab Center
RRTC Training Office - Room 506
1717 Sixth Ave., South
Birmingham, AL 35233-7330

A Step-by-Step Guide to Training and Managing Personal Assistants (1998)

Volume 1: Consumer Guide

Volume 2: Agency Guide

Research and Training Center on Independent Living (RTC/IL)

785/864-4095

4089 Dole Building University of Kansas

Lawrence, KS 66045

Taking Care of Yourself While Providing Care (2000)

Richard Holicky, M.A.

Craig Hospital Research Department

303/789-8308

3425 Clarkson St.

Englewood, CO 80110

Website: <www.craighospital.org>

- \$5.00
- A guide for those who assist and care for their spouses, parents, and other loved ones who have spinal cord injuries

ORGANIZATIONS

National Database of Educational Resources for SCI

The Institute for Rehabilitation and Research (TIRR)

713/797-5944

1333 Moursund, B-107

Houston, TX 77030-3405

- This organization can do a free search to locate materials related to all aspects of the training and management of personal care assistants

The Research and Training Center on Independent Living (RTC/IL)

University of Kansas

785/864-4095

4089 Dole Building

Lawrence, KS 66045

- Offers information and materials on training your personal care assistant

3. Attendant Care Resources

AUDIOTAPES

Busting Loose to Independence: Through Personal Attendant Services (1989)

RRTC in Community Integration for Individuals with SCI

Baylor College of Medicine

713/797-5945

FAX: 713/797-5982

1333 Moursund, B-107

Houston, TX 77030-3405

Available in English and Spanish

- A series of four audiotapes that covers every aspect of Personal Care Assistants, from the decision to hire them to the details of finding, keeping and firing them

VIDEOTAPES

Personal Assistance Services Video Series (1993)

The Consumer: Issues and Answers

The Provider: On Being a Personal Assistant

The Community: A Vision

Shepherd Center

404/350-7473

2020 Peachtree Rd. NW

Atlanta, GA 30309

Attendant Care Basics: An Orientation

Partners in Independence: The PCA's Role in Pressure Sore Prevention

One-to-One (maintaining a Good Relationship with your PCA)

Available on loan from:

Spinal Cord Injury Network International

800/548-2673

3911 Princeton Dr.

Santa Rosa, CA 95405-7013

Website: <www.spinalcordinjury.org>

Personal Assistant Recruitment (1994)

Marionjoy Rehabilitation Hospital

26W171 Roosevelt Rd.

Wheaton, IL 60189-0795

3. Attendant Care Resources

SELF-CARE MANUALS

Self-care or patient education manuals can be a great resource to use when training your personal care assistant. Most of the following manuals have chapters on attendant care, and have detailed chapters on bowel, bladder, and skin care, as well as information on range of motion and exercise programs for individuals with SCI.

Pathways to Health: You Do Have A Choice (\$7.00)

Kenneth A. Gerhart

Craig Hospital Research Department

303/789-8202

3425 S. Clarkson St.

Englewood, CO 80110

Website: <www.craighospital.org>

- Focuses on making healthy choices for people living with SCI

Spinal Cord Injury Patient Education Manual (\$72.00)

Aspen Publishers, Inc.

800/638-8437

200 Orchard Ridge Drive, Suite 200

Gaithersburg, MD 20878

Contact: Eric Lehto

Spinal Cord Injury: A Manual for Healthy Living (\$65.00)

The Institute for Rehabilitation and Research (TIRR)

Division of Education

713/797-5944

1333 Moursund, B-107

Houston, TX 77030-3405

Spinal Cord Injury Homecare Manual (\$60.00)

Kessler Institute for Rehabilitation

201/731-3600

1199 Pleasant Valley Way

West Orange, NJ 07052

Contact: Marilyn Homick, Patient Education Coordinator

The Spinal Cord Injury Handbook for Patients and Their Families (\$15.45)

Richard C. Senelick and Karla Dougherty

HealthSouth Press

800/688-0737

9119 Cinnamon Hill

San Antonio, TX 78240

Website: <www.healthsouth.com>

3. Attendant Care Resources

Yes, You Can!: A Guide to Self-Care for Persons with Spinal Cord Injury (\$15.00)

Paralyzed Veterans of America

Education Department; c/o Office Services

800/424-8200

801 N. 18th Street NW

Washington, DC 20006