

Ann Arbor Center for Independent Living

University of Michigan  
Model SCI Care System

Michigan Resource Guide  
for Persons with Spinal Cord Injury



# Personal Assistance

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## Introduction

After you sustain a life altering spinal cord injury, you may need some assistance with tasks that you used to complete without a thought. The relationship between a person requiring assistance and those who provide it can be either a wonderful experience or frustratingly difficult. It can impact the quality of life substantially for all involved. This section will provide some resources and basic information on the topic,

as well as Dennis Lovely's account of hiring and managing personal assistants. Also, in this section is a story about a four-legged assistant and information on where to find one. Animal helpers can add substantially to your level of independence and comfort in the community and at home.

By Kim Sherwood OTR

**People In Action**

**Personal Account**  
by Dennis Lovely

I have been a quadriplegic for 21 years as a result of a diving accident. My experience in hiring, managing, and keeping Personal Assistants (PA), runs the gamut from rewarding to disappointing. I would like to share with you some tips that may help you avoid disappointment.

- Often the person has already been pre-screened by an agency, but the initial phone call offers a good chance to accept or eliminate someone, prior to a face-to-face interview based on *your* needs.
- Dependability is, perhaps, *the* most important attribute for a PA to have. If they show up late, or call at the last minute to postpone for another day, it's a definite *red flag*.
- Have a simple application form for them to fill out. This imparts a feeling that this is a real job, not just an informal verbal agreement.

- Last, and probably most important, check out previous employment references. Like most other endeavors, experience is the best teacher. Talking to other "veterans" of the hiring process can also be helpful. Good Luck!

**Basic Information**

**What's a PA?**

A Personal Assistant (PA) is an individual hired to assist a person with a disability with everyday tasks she or he would do independently if a disability did not prevent them. Such tasks, depending on the person's specific disability, can include personal care (bathing, dressing, toileting, grooming, transfers, etc.), household maintenance (cleaning, cooking, changing a light bulb, yard work), cognitive tasks (balancing a checkbook, making decisions), and other life activities such as travel assistance, clerical tasks, and pet care.

**How do I get a PA?**

Personal Assistants are obtained and paid in a variety of ways. Some people have the skills and financial resources to hire, manage, and pay their PA privately. Others have the skills but not the resources, and so utilize financial assistance programs (see *Potential Funding Sources* below). Still others lack management skills or the time and energy to manage their own PA, and they choose to use a home health agency or other direct care provider.

For the person who plans to manage their own PA, once the payment issue is addressed, the search for the right PA(s) is the next challenge. If hiring directly, the following are likely places to advertise: local Center for Independent Living; student employment offices at colleges and universities; local newspaper; church bulletin; local bulletin boards; and general employment offices. It is helpful to prepare a list of screening questions to ask when potential applicants call and to prepare an application form.

After selecting several promising candidates, the next step is to schedule interviews. For safety reasons, it is advisable to either interview them away from home, or if home is the best place, then to have at least one other trusted person around during the interview. Use the application form to help identify the candidates, and most importantly, CHECK REFERENCES! It is also helpful to schedule several interviews in a row, and to have reading material or some other pastime available in case of no-shows.

### Looking for Personal Assistant?

Your local Center for Independent Living is a good place to get information on resources for personal assistants in your area.

Another resource for locating good personal assistants in your area is through referrals from your healthcare team. Your physician, nurse, therapist or social worker may be familiar with particular individuals or agencies that provide services in your area.

You have several options regarding hiring personal assistants. These are:

1. Use a nursing agency. This is the most expensive option as you must pay for the agency's overhead costs, including scheduler, professional staff supervision, as well as the cost of the person working directly with you. Also, agencies sometimes have more rigid guidelines about what a non-skilled nursing assistant can provide assistance with as compared to a licensed nurse. Examples of this type of care include bowel and bladder management, minor wound care and suctioning and/or trach care. The advantage of using an agency is that you have a person to call if no one shows up (some agencies do try to find back-up assistance for you), and you are not required to handle paying the personal assistants directly. Also, professional agencies usually bond their employees, which would protect you in case of theft or damage to your home or possessions.

2. Use a smaller agency set up by a personal assistant (without the professional supervision of a nurse), or check if there

are any cooperatives of personal assistants in your area. You need to be aware of whether the agency or cooperative will be handling the personal assistants' taxes and insurance coverage. You may also want to check on how much training is provided to the employees, and what their back-up policy is.

"Independent Living is not doing things by yourself. It is being in control of how things are done."

*-Judy Heumann*

3. Hire an individual directly. In this case, you would be responsible for checking the person's references, and managing the scheduling/back-up for yourself. You would also have to become a "household employer" of record for the PA if you pay them over \$1200 per year (see IRS guidelines for "household employer" information and requirements). Hiring your own assistants gives you more control, but also takes more effort

and planning on your part to manage.

Paying for your personal assistance needs is often the most challenging issue. If you qualify for Medicaid, you may be able to get financial assistance from the Home Help Program to pay for personal assistance. If you qualify for coverage under Michigan No-Fault Auto insurance, it may pay some or all of the costs. Also, if you are a veteran, check with the Veterans Administration for coverage in your particular situation. If you are employed, you may want to check with your local Michigan Jobs Commission office for other options for assistance, including the Personal Assistance Reimbursement for Employment Program (PASREP), which may be able to provide some funding.

### **Then what?**

Once the interviews are done and references are checked, an offer of employment is made to the selected candidate(s). If one or more candidates seemed promising but were not selected, it is a good practice to ask them to consider doing occasional fill-in work

when regular PAs are out ill. The first shift, and often the first several shifts, are training time for the new PA, and require extra patience and additional clear concise communication on the part of the individual receiving assistance. Some people learn better by demonstration, especially when the task is detailed or potentially hazardous in some way, such as a transfer. It is important to have another PA or family member available during this time to do the demonstrations.

### **What if we don't work well together?**

Periodically training updates may be necessary, depending on the skill level of the work and the abilities of the PA. At times, circumstances such as schedule changes or poor work quality may necessitate the termination of a PA's employment. If there are problems in the working relationship, it is important to follow a fair disciplinary procedure. One or two verbal warnings followed by a written warning should precede termination except in cases where the employer feels in danger. In those cases, termination should be handled quickly

and in the presence of a trusted PA, friend, or family member, to maintain a level of security.

### **Communication is the Key**

The key to maintaining a good relationship is ongoing clear, respectful communication. The PA needs to know what they can do to continually improve their performance, and they also need to know what they're doing well. Plenty of positive feedback and honest, appropriate praise for a job well done will help the PA to be proud of their work and their profession.

## Resources for Personal Assistance

**Local Center for Independent Living:** Many CILs have either referral lists for personal assistants or are affiliated with a local cooperative of personal assistants. Call them for local resources.

Look in **local telephone directory** under “Home Health Services” for agencies providing service in your area. Or online, use **google.com** to search in your local area: e.g., type (southeast michigan "home health services")

Check in **local newspaper classifieds**, usually in section labeled “domestic/childcare” or “part time/contract” employment– you can place an ad and recruit your own PA.

Contact Michigan Visiting Nurses for local assistance  
[www.vna.org](http://www.vna.org)

Contact local “Area Agency on Aging” and/or “Senior Alliance” for the names of local home care agencies.

On the internet, search **Google.com** for “Michigan errand service”

To order and read if you are about to hire a personal assistant:

**Your Responsibilities as A Household Employer**

By Shirley Coombs, MSA  
(c) 1998  
Ann Arbor Center for Independent Living  
3941 Research Park Drive  
Ann Arbor, MI 48108  
734-971-0277  
734-971-0310 (TTY)

**Spinal Network:  
The Total Wheelchair  
Resource Book  
3rd Edition**

Published by Nine Lives Press, Inc.

**Chapter 8, Personal Assistance Services.**

Distributed by Leonard Media Group.

P.O. Box 220

Horsham, PA 19044

888-850-0344 x4

Important Web Links

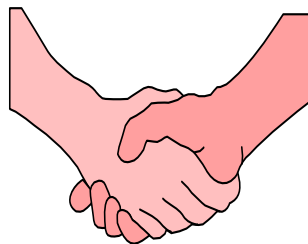
**PAS Center for Personal Assistance**

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

A Personal Assistant advocacy site.

**Independent Living Institute**

[www.independentliving.org/assex/index.html](http://www.independentliving.org/assex/index.html) An online matching service.



**HOME CARE AND HOSPITALS**

**Michigan Hospital Association.**

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

**VISITING NURSES**

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

**AREA AGENCY ON AGING AND/OR SENIOR ALLIANCE**

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

Potential Funding Sources

◆ **Washtenaw Department of Human Services Adult Home Help Program**  
734-481-9110

Provides funding for personal assistance for personal care and house keeping. Assessment is done by caseworker who then determines level of funding. Usually an exception process is required when a person needs more than \$333 per month for Personal Assistance Services.

**Eligibility:**

- 1) Income limits equivalent to Medicaid eligibility
- 2) Documented need for Personal Assistant Services.

◆ **Community Support and Treatment Services / Developmental Disabilities Services**

734-544-3050

Formerly known as Washtenaw County Community Mental Health, CSTS provides funding for personal assistance for personal care, housekeeping and community participation. Amount and type of assistance is determined through the Person Centered Planning process.

Eligibility:

- 1) Flexible/reasonable income limits
- 2) Disability onset prior to age 22 and disability substantially limits 3 or more of a list of 7 activities.

◆ **MI Choice Medicaid Waiver Program.**

734-213-6704

Administered by Area Agency on Aging and Macomb-Oakland Regional Center. Choice provides funding for personal assistance for personal care and home making. Assessment is done by caseworker who then determines level of funding.

Eligibility:

- 1) Income limit 3x Medicaid limit
- 2) Documented need for service up to 23 hours

per day (though very few participants are awarded more than 2 to 4 hours per day).

◆ **Personal Assistance Services Reimbursement for Employment Program (PASREP)**

734-971-0277

Administered by Ann Arbor Center for Independent Living, the PASREP program provides funding for personal assistance for personal care and housekeeping. Employer with disability hires and pays PA, submits receipts to program, and is reimbursed up to a predetermined level. Assists persons with disabilities who want to work but can not afford full cost of their PAS.

Eligibility:

- 1) Must have employment or promise of employment for a minimum of 24 hours per week
- 2) Documented financial need.

◆ **Medicare**

800-482-4045

Medicare pays for very limited personal assistance services when one is either “homebound” or has recently been hospitalized. There is a current advocacy effort to change

the “homebound” requirement.

See:

[www.amendhomeboundpolicy.homestead.com/](http://www.amendhomeboundpolicy.homestead.com/)

People In Action

Parker By My Side

By Barb Schoen

Parker came to me in March of 2001, and I truly can't imagine life without him. He is tirelessly dedicated to me. He's always on the job. He will awaken from a dead sleep at the sound of a pencil dropping on the floor or the all too common “oh-oh” he hears me say when I drop something on the floor.

A common task for service dogs is to assist their owners in opening doors; a complicated task, which Parker does with ease. He, however, is responsible for opening more doors than you can imagine. Everyone is happy to see us. We are always noticed and given preferential treatment. I have come to believe that

99.99% of the world is dog lovers. I suspect the animal phobic people must have to flee to avoid being run over by the other 99.99% as they rush to see my beautiful retriever.

*Barb Schoen and her canine friend, Parker.*



As we move through our very busy day, we are inundated with comments like beautiful, gorgeous and so on. On occasion I respond with a thank you followed by a pause and “oh you were talking about the dog.” On the down side, it is really hard to tell people he is working and can’t socialize. I promise them that he gets plenty of pets from me and he gets to be a regular dog at home. Although at home he plays with the cat and retrieves the ball, he is always on duty, never leaving my side.

This is a tough job with little pay (he literally works for food). Our days are filled from morning to night, not what you might expect for a forty-year-old woman with quadriplegia.

I am currently a doctoral student at Michigan State University in the Rehabilitation Psychology Program. I am starting my own company dedicated to helping persons with disabilities maximize their abilities and independence. Through it all, Parker is at my side grabbing cat naps...uhhh...dog naps when he can.

Many people ask what specific tasks he can perform. He picks up papers, quarters, my drivers license, credit cards, books, water bottles, pencils, CD cases, literally anything he can fit in his mouth. He has learned to work with me not letting go until he feels I have a firm grasp on the items. He helps me open the fridge, he gets the phone and performs countless other retrieval tasks. It is entertaining to see him strut when he knows he’s done a good job. His support is unconditional; he doesn’t lose his patience even after the third retrieval of an item I keep dropping.

Having a service dog is very rewarding; but it is also a commitment. The dogs need their shots, their nails trimmed and their coats groomed. They must be fed, usually in the morning and night, and be given water and bathroom breaks throughout the day. These dogs rely on their owners as much as their owners rely on them. I am blessed to have Parker by my side. He helps me maximize my independence so that I can help others. That’s really the way it should be. I think life is so much more rewarding when it’s filled

with all of God's creatures helping one another.

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Resources for  
Animal Helpers

**PAWS WITH A CAUSE**

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

800-253-7297

Trains Assistance Dogs nationally for people with disabilities and provides lifetime team support, which encourages independence.

Michigan Newsletter:

**Dogs For Dignity**

4646 South Division

Wayland, MI 49348

616-877-7297

800-253-7297

email: [paws@alliance.net](mailto:paws@alliance.net)

**CANINE  
COMPANIONS FOR  
INDEPENDENCE**

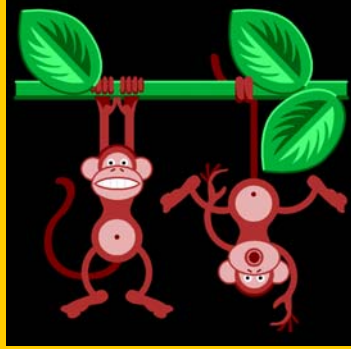
P.O. Box 446

Santa Rosa, CA 95402-

0446

707-528-0830

Trains dogs to serve as arms, legs, and ears for persons with a disability.



**HELPING HANDS –  
MONKEY HELPERS  
FOR THE DISABLED**

541 Cambridge Street

Boston, MA 02134

617-787-4419

[www.monkeyhelpers.org/  
contact](http://www.monkeyhelpers.org/contact)

This organization supplies trained capuchin monkeys to assist people with tetraplegia with a variety of tasks such as getting drinks of water, turning lights on and off, and dressing. These monkeys are free if you meet certain criteria.

**For information about  
service animal  
requirements under the  
Americans With  
Disabilities Act, call the**

U.S. Department of  
Justice's toll-free ADA  
Information Line:

800-514-0301 (voice)

800-514-0383 (TDD)