

Personal Care Attendant

Spinal Cord Injury
InfoSheet



Level - All Audiences

INTRODUCTION

Between 40 and 45 percent of individuals with spinal cord injuries (SCI) need personal assistance with some daily activities [1]. It is understandable that the majority of persons needing assistance have higher levels of injury. They may need personal care assistance with getting in or out of bed, managing bowel and bladder issues, bathing, and dressing. Some individuals may need someone to drive, shop, and clean for them too. However, there is also a growing percentage of persons with lower levels of injury needing assistance as they get older. They may need assistance with household activities as they grow older and experience increased pain or fatigue.

ASKING AND RECEIVING

It may not be easy at times to ask for and receive assistance. This difficulty usually stems from two notions of thought.

First, some people may not ask for help because they do not want to “burden” others, especially family members. If you feel this way following SCI, ask yourself if it would be a burden on you to help a loved one in need. Probably not. However, many people with SCI still do not ask for the help they need.

We are part of a family; we are part of a society; and we all need each other. We all need help at times, and we rely on each other in many ways, and most people gladly help family and friends if needed. Children are dependent on their parents and rely on them for care, and children commonly assist their parents as they age and become increasingly dependent. It is a natural state. Likewise, we function as a society helping each other throughout life. Health care professionals help us when we are sick; teachers help educate us; and police officers and fire fighters help protect us from danger. In fact, most jobs provide some type of service for people. The reality is that there is no shame in

asking for and receiving help when you need it. And you will probably make your everyday life more of a burden on you if you do not get assistance when you need it.

A person's impression of "independence" is the second problem notion of thought. Some people may refuse assistance if offered because they believe that being independent means doing things without the help from others. However, the reality is that people who refuse help are less independent than people who ask for and receive help. Independence has little to do with what you can do. Independence is having the freedom to choose what you want to do. For example, people who do not have the ability to drive can still choose to go somewhere if they have assistance. When you get assistance, you have the opportunity for independence. It is that simple.

FINDING A PCA

There really is no “best” way to find a Personal Care Attendant (PCA). You may need to use a number of ways to find people who might be interested in the job. If you qualify for services, you might start your search by checking with your State Department of Rehabilitation Services to see if there's a local program to help you find a PCA. Another option is to advertise in your local newspaper describing your need for PCA services. A classified ad will cost money to purchase, but you can reach a lot of potential candidates who are searching for employment. If you place an ad, it is a good idea to advertise on weekends because that will reach the most people. Another option is posting flyers in community areas likely to catch the eye of persons in the field of providing personal care. For example, you might put a flyer on a hospital or nursing home bulletin board. You can also post a flyer at a local college in the schools of nursing, occupational therapy and physical therapy. Finally, people often learn of jobs through word of mouth, so let people know you are searching for a PCA.

INTERVIEWING FOR A PCA _____

When you get calls from people interested in the job, you should schedule an interview with each person. This is your chance to get to know the person, and it gives the person a chance to find out more information about the job. You should clearly explain the types of tasks that your PCA will need do, and you should invite questions from the candidate to make sure he/she understands your needs. Many duties are of a very personal nature, so you want to be sure candidates are comfortable doing these tasks. Describe all the duties involved such as lifting, bathing, bowel and bladder programs, housecleaning, or grocery shopping. Discuss pay. Also, tell them what education and training you will provide.

You can save time by preparing a list of questions to ask each candidate. A few examples might be:

- ◆ Do you have previous experience?
- ◆ Do you have physical problems that prevent you from lifting or pulling?
- ◆ Will you cook and do housework?
- ◆ Do you have a driver's license, and are you willing to drive?
- ◆ Do you have dependable transportation to and from work?
- ◆ How much money do you need to make?
- ◆ Do you feel comfortable assisting with more "sensitive" personal care such as bathing, bowel and bladder care?

If you are having problems deciding on a candidate, you might make a checklist of your needs and the personal qualities that you want in a PCA.

- ◆ Is the person dependable and on time?
- ◆ Is the person trustworthy and honest?
- ◆ Is the person able to follow instructions?
- ◆ Is the person someone who is friendly?
- ◆ Is the person someone you can be friends with?

Based on your interviews, you can select the best candidate for you. Once you select someone, *always ask for references*. If a candidate does not provide references after you ask, you may want to choose another person who will provide references because *you should always check all references before hiring* someone who is going to come into your home. Talk with previous

employers to learn about the qualities that you want in an employee. You might get the candidate's driver's license number to ask the local police to run a security check on the person. You are ready to hire the person who checks out and best fits the qualities that you desire. Initially, you might hire the person on a temporary basis. This will give both you and the PCA time to get to know each other and find out if there is a good working relationship.

EDUCATION AND TRAINING _____

Most PCAs need education and training on general issues associated with SCI. You can find and print information sheets from reliable sources on the Internet. Gives these sheets to your PCA to read.

Even if you find a PCA with a lot of experience, you also have unique needs. Although all issues are important, your bowel, bladder, skin, and respiratory care must be understood by your PCA. Communicate your bowel and bladder needs clearly. Make sure you stress the importance of daily skin care, and your PCA should know how to conduct daily skin checks and spot problems. PCAs need to know about respiratory sickness too. Flu and pneumonia can be life-threatening for most people with SCI. This fact makes it important to have PCAs understand these dangers and work to prevent spreading these conditions. Washing hands should always be done often to help prevent the spread of germs. PCAs who are sick with a cold or flu should avoid contact when possible. If contact is unavoidable, PCAs should wear a mask and wash hands more often.

For individuals on a ventilator, PCA training on all the mechanical works of a ventilator can mean life or death. There should also be an emergency plan for ventilator problems and failures.

PARTNER OR SPOUSE VS. PCA _____

A spouse or partner is often the first to provide personal care following injury. Although this arrangement is initially common for couples, the partner/caregiver role can be unhealthy if it continues long following injury. They may feel it is their "duty". Some family members do not want an outsider caring

TOP 10 REASONS PCAs QUIT THEIR JOBS

- 1 Their initial job description was incomplete or keeps changing.
- 2 The method and order in which they must perform their duties are illogical, inefficient and waste time.
- 3 Their working environment is messy, unpleasant, disorganized, etc.
- 4 They're not paid enough, don't get appropriate raises or don't feel their work is appreciated.
- 5 They feel another PCA is favored over them.
- 6 The employer (YOU) is either too passive or too aggressive in his/her style of interaction.
- 7 The employer is dishonest about the hours worked, the salary owed, or has inappropriate expectations such as monetary loans or sexual favors.
- 8 There are unreasonable duties—those the employer is able to perform alone, those which cannot be performed in the allotted time or those which are too tightly supervised.
- 9 The employer is intolerant of honest mistakes, the need for sick time, etc.
- 10 The employer doesn't respect PCA's personal life and expects that his or her needs should take priority over all else in the PCA's life.

Source: Home Health Aides: How to Manage the People Who Help You, by Al DeGraff, 1988, Saratoga Access Publications, P.O. Box 1427, Fort Collins, CO 80522-1427.

for their loved one. However, it is the individual with SCI who needs to decide what help he/she needs and who will provide it.

Although a spouse or partner might provide care at times, it is generally recommended that the primary care provider be someone other than a family member. This separation of roles allows individuals with SCI to be independent of family members and avoid unnecessary conflict with loved ones. Additionally, this separation ensures that family members do not become resentful of the added responsibilities or duties in the relationship.

Unfortunately, some couples have no option other than for a partner or spouse to be the primary caregiver. In this instance, it is very important to keep the partner/spouse role separate from the caregiver role. One way to do this is to have a routine that keeps the caregiving activities separate from those of a partner. Couples also need to have occasional time apart. Keeping the partner/caregiver roles as distinct and separate as possible will help you to avoid confusing and blurring of the partner role with the caregiver role, which is healthier for a couple's personal relationship [2].

FUNDING

The US Department of Labor's Wage and Hour Division administers and enforces the federal minimum wage law. The federal minimum wage for employees is currently \$5.85 per hour, and the minimum wage

will increase over time to \$6.55 per hour effective July 24, 2008 and to \$7.25 per hour effective July 24, 2009 [3]. Many states also have minimum wage laws. In cases where an employee is subject to both the state and federal minimum wage laws, the employee is entitled to the higher of the two minimum wages.

Many people cannot afford a PCA without financial assistance. You may qualify for local or state programs that can help in paying a PCA. You might contact your local Independent Living Center, State Department of Rehabilitation Services or, for veterans, the Department of Veteran's Affairs. In some cases, private insurance may pay for "skilled nursing care," which may provide some aspects of personal care. If you are getting a financial settlement for your injury, it is important to include the projected lifetime costs for a PCA.

Like most things in life, you get what you pay for when it comes to a PCA. A reliable, dependable and skilled PCA is going to cost you. You want to make the job as appealing as possible to hire and keep the best possible PCA. Utilize all of the outside services that you qualify for to pay for a PCA, and you can also pay what you can afford out of pocket. Give occasional bonuses if you can, too.

Finally, you should probably talk with an accountant about any possible issues related to the Internal Revenue Service [4]. Before you can know how to treat payments you make for services, you must first know the business relationship that exists between you and

the person performing the services. If you have an employee, you may be responsible for Federal Income Tax Withholding, Social Security and other taxes as an employer. You may also need an accountant to help you with what you can and cannot claim on your personal income tax returns.

WORKING WITH AN PCA _____

A PCA is often your friend and employee. It is up to you to balance the two roles. The first step is to make clear that a PCA's role is helping you with daily activities that you cannot do for yourself, and it is you who decides what assistance is needed.

There are times when you need to be assertive, and you need to also be flexible sometimes. If there is a specific way that your care needs to be done, give the PCA clear directions on what needs to be done and the proper techniques involved. However, a PCA is a person, too. Although you are in charge of your care, your PCA may have a different approach to providing the same quality care. So you need to be reasonable in listening and accepting different ideas and opinions. It

REFERENCES _____

- 1 Accepting New Help
A brochure from Craig Hospital
303-789-8202
www.craighospital.org/SCI/METS/acceptingNewHelp.asp
- 2 Healthy Living: Relationships
An article from the Pushin' On, Vol 19[1], 2001.
University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=36069
- 3 U.S. Department of Labor
1-866-4-USWAGE
www.dol.gov/esa/whd/flsa/

is also nice to express your appreciation to your PCA for the help he/she is providing for you. Finally, it is important that you are understanding if your PCA has a "bad" day or makes a mistake. Hopefully, you will find that you can be flexible but still keep a professional relationship.

Finally, you cannot rely on one PCA all the time. If your spouse or partner is your primary caregiver, it is very important that you find a way to give him/her personal time for rest and enjoyment. Your PCA also needs days off, and there are unexpected circumstances that require absences from work. Therefore, you need to plan ahead. Make sure you have options and the ability to call on multiple sources if needed.

CONCLUSION _____

Many individuals with SCI need assistance with daily activities. Although the process of finding, hiring, training, and supervising a PCA is a necessity, asking for and receiving help may be difficult for some people. But a PCA can enhance your independence and quality of life.

4 The Internal Revenue Service
800-829-1040
www.irs.gov/

OTHER RESOURCES _____

Center for Personal Assistance Services
1-866-PAS-9577 (free call)
www.pascenter.org

State Rehabilitation Providers
1-800-772-1213 (free call)
www.ssa.gov/work/ServiceProviders/rehabproviders.html

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