



Shepherd
Center

How to Successfully Hire and Manage a Personal Care Assistant

for People with Spinal Cord Injury



Brain & Spinal Injury
Trust Fund Commission

Developed and Created by Shepherd Center.
Based on previous work by Debra L. Burdsall, OTR, Santa Clara Valley Medical Center.

Design by Edward Tharp

Copyright © 2013 by Shepherd Center. All Rights Reserved. No part of this publication
may be reproduced without the prior, written permission of Shepherd Center.

Shepherd Center, located in Atlanta, Ga., is a private, not-for-profit hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury or brain injury. Founded in 1975, Shepherd Center is ranked by *U.S. News & World Report* among the top 10 rehabilitation hospitals in the nation and is a 152-bed facility. For more information, visit Shepherd Center online at shepherd.org.

Table of Contents

1 What are “Personal Assistance Services”?

1 Options for Personal Assistance Services

- 1 Family Member/Spouse
- 2 Hired Employee
 - Have a Back-Up Plan
 - Using a Home Care Agency
 - Finding a Privately Hired, Non-Agency Caregiver
- 3 Creating an Ad

3 Screening and Interviewing a Prospective Personal Care Assistant

- 3 Personal Needs Assessment
- 5 Think About Caregiver Requirements
 - The Interview
- 7 Employment References
 - Making a Decision
- 9 Guidelines for Attendant Training
 - Your Relationship with Your Personal Care Assistant
- 10 Funding Issues and Resources
 - Medicaid Waiver Programs
 - Personal Assistant Services Attendant Timesheet
 - Responsibilities as an Employer
- 13 Personal Care/Caregiver Resources
 - General SCI Resources

2020 Peachtree Rd. N.W.
Atlanta, GA 30309
404-352-2020

shepherd.org

Copyright © 2013 by Shepherd Center. All Rights Reserved. No part of this publication may be reproduced without the prior, written permission of Shepherd Center.

What are “Personal Assistance Services”?

For many individuals with spinal cord injury (SCI), coming to terms with the injury includes an acceptance that physical limitations may require them to get help from someone else to complete activities of daily living. Learning how to live with this new need for assistance, without compromising independence and dignity, can be challenging. There are many issues to consider when planning for personal care needs, and several will be addressed in this guide.

Personal assistance services include a variety of activities that are determined by the individual needs of the person with SCI. Personal assistance services can range from assistance with grocery shopping and meal preparation to bathing, and bowel and bladder care. A personal care assistant is someone who assists an individual with spinal cord injury with his or her daily living activities. The personal care assistant is also referred to as an “attendant” or “caregiver,” whether the care is being provided by a spouse, parent, friend or hired employee.

Options for Personal Assistance Services

Family Member/Spouse

A person with SCI should first consider whether a family member should take on the role of personal care assistant. There are several factors to think about when making this decision.

Often, the decision is made based on financial considerations, without taking into account other options or thinking about the potential toll that providing care may take on the personal relationship. When a family member – whether it’s a parent, spouse, son or daughter – assumes the role of personal care assistant, the lines between multiple roles can blur. Providing personal care can put stress on any relationship and can be particularly hard on a marriage. For example, it may be difficult for a partner who has the responsibility of performing bowel and bladder care to be involved in an intimate relationship, as well.

The positive aspect of having a spouse or significant other in the caregiver role is familiarity. Having someone with whom a relationship has already been established involved in your personal care can be a strong factor in the decision-making process. For some people with SCI, economic necessity is the primary reason the spouse or family member assumes the role of caregiver. Regardless of the circumstances, whenever a spouse or significant other takes on the personal care assistant role, it is helpful for both parties to take time to clarify roles and plan together how care should be given. Other options for personal care assistants include friends and family members other than spouse or significant other. Many of the issues discussed previously are still important considerations. They include communication skills, comfort level of both parties, level of commitment, etc.

A couple should consider all aspects of their relationship and how it would be affected before making a decision for one to become a caregiver for the other. Important

aspects to consider include the spouse’s ability to provide care, communication skills, balance of power, respect and self-esteem.

One of the most important factors – but perhaps the most difficult to assess – is whether providing care to a spouse is even within the potential caregiver’s capability or comfort level. The spouse must be trained by rehabilitation professionals in all of the care and demonstrate proficiency in each task. The spouse must also be comfortable with delivering the care *before* committing to being a caregiver.

Good communication skills and awareness of the balance of power are vital to the relationship between the person with SCI and any personal care assistant. It may be difficult to communicate and clarify needs for fear of being perceived by the caregiver as too demanding. Or, because of a lack of control, the person with SCI may demand more of a spouse than he or she would of a personal care assistant who is an employee. Couples need to be especially aware of the balance of power in the relationship. In the situation where a spouse becomes a caregiver, neither party should be perceived as too passive or too demanding. Creating such a balance in the relationship, which may already be strained, can pose a challenge.

Respect and self-esteem are two important aspects of a relationship that may be adversely affected when a spouse takes on the role of personal care assistant. Both the person with SCI and the caregiver must respect personal boundaries, desire for individual space and the need for clear communication. Self-esteem, which may be affected following an injury, may be further affected if a spouse must provide personal care that the person with SCI was previously able to do independently. Both spouses should discuss how to maintain self-esteem. They may want to involve a counselor to assist, if possible.

Often a sense of obligation clouds the issue of a spouse becoming a caregiver and makes it difficult to assess whether a spouse would make a good personal care assistant. It is important to consider how the potential loss of personal time and space, and sense of individuality, would affect the relationship between the person with SCI and the spouse.

To avoid unnecessary confusion and conflict, the couple must devise a system of communication of care needs before caregiving begins. A case manager or counselor may be able to assist the couple in devising such a plan.

Hired Employee

Hiring a personal care assistant, someone who is employed by the person with SCI, may be the option that affords the maximum amount of control and input into caregiving. A personal care assistant who is an employee works for the person with SCI. The most important part of the job is to take direction and provide care in a manner that is suitable to his or her employer.

Have a Back-Up Plan

Regardless of who takes the role of personal care assistant, it is imperative to have a back-up plan in place in case the assistant gets sick, quits without notice or is unable to provide care for any reason. Being without a personal care assistant can be a frightening and intimidating experience that is best avoided. A well-thought-out plan that has been prepared before such an occasion occurs is the best way to handle the situation. You should develop a list of people who are willing to serve as a back-up attendant. These attendants could include family members, friends, or school or organizational associates. Find out the time of day and day of the week each person on the list is available.

Using a Home Care Agency

There are a couple of options for hiring a personal care assistant, one of which is using a home health agency. One of the primary benefits of hiring an assistant through an agency is convenience, as the agency presumably handles the screening and application process. Also, an agency will often provide back-up care in the event the attendant is sick or unexpectedly fails to show up for work. The disadvantages of hiring an assistant through an agency include higher cost in most cases, as well as a lack of control over choosing a caregiver. These personal care assistants typically require specific training as to the needs of the individual with SCI, as most assistants do not receive such training in advance.

Finding a Privately Hired, Non-Agency Caregiver

There are several avenues to pursue when seeking a personal care assistant. The individual with SCI should assess the situation and think about which recruitment method(s) might work. Before attempting to find an assistant, the person with SCI should fully consider their specific needs, such as the times of day care is needed most, the types of caregiving activities required and how these could be consolidated into blocks of time.

Some methods for locating caregivers in the community include:

- Posting an ad on a bulletin board at the local community college or university's career placement center.
 - Bulletin boards may be physical or online. Call the school's switchboard to find out if there's an online version that's general or if relevant departments have their own.
 - It may be helpful to focus on schools that offer specific curriculum for nursing or occupational/physical/recreational therapy. Often the students in such programs need experience in the field before graduation. Hospital bulletin boards may be a good source, as staff members may be looking for extra work.
- Advertising on Craigslist and other online sites.
- Posting in a local church bulletin.
- Contacting local vocational rehabilitation agencies.
- Contacting local unemployment or social service agencies.

The person with SCI might also contact a local independent living center. One of the key services provided by independent living centers is to assist community members with the process of locating caregivers. Independent living centers may keep a listing of potential attendants who may have been preliminarily screened by the staff. Some even offer classes to train the person with SCI, who may need assistance with the hiring and management process, or the prospective attendant. You can find your local independent living center by visiting www.ilru.org/html/publications/directory/index.html.

Finally, never underestimate the power of word of mouth. Get the word out by telling friends, family members, organizational associates and neighbors of the need for a personal care assistant. A prospective attendant referred by a friend may be the best bet. Also, talk to other individuals who have attendant care needs in your community to find out who they are using. Often, one attendant will work for two or more people.

Creating an Ad

One of the most common ways to find an attendant is through an advertisement placed on a website like Craigslist or a local publication, such as a newspaper. The first step is to create an ad that briefly states the needs of the person with SCI and a description of the type of person being sought, while hopefully sparking the interest of a prospective attendant.

The ad should include a brief description of the types of assistance needed, hours and days required, part-time versus full-time status, live-in versus live-out, specific requirements for the position (such as heavy lifting, driver's license, non-smoker, etc.) and salary. You cannot list preferences based on sex, age or race as this is considered discrimination and is against the law. Finally, include your contact information and hours you can be contacted. For security reasons, it is not advisable to list a full name or address in the ad.

Sample Advertisements

Live-in companion needed to share home with man with tetraplegia in Atlanta, GA. Personal care, cooking, yard work and cleaning assistance needed in exchange for private room, board and \$1,000 per month. Contact Mark at _____ weekdays.

Live-in companion sought to share home in a quiet setting with female with a disability. Room, board and salary in exchange for help with house, meals and errands. Two days off per week. Contact Rosie at _____ .

Part-time skilled personal care attendant sought for weekday mornings. Non-smokers only. 15 hours per week. \$9/hour. Contact Connie at _____ weekdays.

Live-in attendant needed for college student. Must be willing to do personal care. Flexible hours, good salary, split household expenses. Contact Brad at _____ .

Aide to assist man with a disability with daily activities. Must be able to drive and cook. 4 hours per day, \$10 per hour. References required. Contact Rudy at _____ weekday evenings.

Flexible hours/room and board plus stipend for mature, responsible female student to assist student with a disability with self-care activities. Personal care involved. Call Lisa at _____ .

Female with a disability needs dependable, intelligent personal care assistant. Pleasant surroundings; must like dogs. Hours negotiable. Personal care involved. Contact Maureen at _____ .

You will need an application for prospective caregivers to fill out so you'll have all the relevant information you need on hand as you go through the hiring process. Here is a sample application.

Personal Assistant Services Attendant Application

Applicant Information

- Name: _____
- Street Address: _____
City/State: _____
Zip Code: _____
- Home Number: _____
- Cell Number: _____
- Email Address: _____
- How long have you lived at this address? _____
- In case of emergency, notify:
Name: _____
- Relationship to Applicant: _____
- Street Address: _____
City/State: _____
Zip Code: _____

Job Experience

- Have you had previous experience working as a personal care assistant, nurse or nurse's aide?
 Yes No
- If yes, please describe your job duties:

- How long were you employed in this capacity?

Please list two previous employers to be used as references:

- Employer Name: _____

- Street Address: _____
City/State: _____
Zip Code: _____
- Home Number: _____
- Dates employed: ____ / ____ / ____ through ____ / ____ / ____ .
- Employer Name: _____

- Street Address: _____
City/State: _____
Zip Code: _____

- Home Number: _____
- Dates employed: ____ / ____ / ____ through ____ / ____ / ____ .

Availability

- Date available to start work: ____ / ____ / ____
- Shifts willing to work:
 Full-time Overnight
 Part-Time Evenings
 Mornings On-call for emergencies
 Afternoons Live-In
- How many hours per week are you willing to work?

- What time are you able to start in the morning?

- How late could you stay in the evening?

- If you are a student, what is your class schedule?

- What is your means of transportation?

Other Information

- Do you have a valid driver's license? Yes No
- Have you been convicted of a felony, misdemeanor or other offense within the past three years?
 Yes No
- If yes, explain:

- Are there any jobs that you would not want to do (for example, drive, bowel and/or bladder care, lifting or other duties listed in job description?)

How did you hear about this position?

Rate of pay acceptable to applicant:

Screening and Interviewing a Prospective Personal Care Assistant

Personal Needs Assessment

In preparation for the screening and interview process, the individual with SCI should conduct a personal needs assessment (see sample below) to clarify those activities for which an attendant's assistance is needed. It is helpful to develop this as a checklist that encompasses all the self-care, housekeeping, grocery shopping, errand running and transportation activities that require assistance. This checklist can be used in the screening and interview process.

It is also helpful to clearly outline expectations for how each task the personal care assistant performs will be completed. In preparing a checklist for a specific aspect of personal care, be brief, put the tasks in the correct sequence and be as thorough as possible. This checklist will be a useful tool for training the assistant, and may help address any differences in opinion regarding how a specific task should be done.

Think About Caregiver Requirements

Before beginning the search for a personal care assistant, there are several things to consider, such as whether the person with SCI would like the caregiver to live-in or just come in for several hours at a time to provide assistance. This, of course, also depends on the level of care that required, as well as space limitations in the home and the need or desire for privacy. If space and personal lifestyle permits, consider offering room and board in exchange for personal assistant services.

It may also be helpful to make a list of characteristics desired in a caregiver. Give careful consideration to factors such as honesty, reliability, consideration, promptness, ability to listen, willingness to learn new or different tasks, and the importance of each of these characteristics. What are the most important and least important, and where can compromise be made? The person with SCI should consider whether they want an attendant with shared interests, and the importance of issues such as the attendant's reliable transportation, smoking, drug and alcohol use, and previous driving record.

It is advisable to screen a prospective attendant before spending time and energy on conducting a full interview for a person who may not be well suited to meet the needs of the person with SCI. A brief phone interview can be a helpful tool for screening individuals who may be interested. The telephone interview can provide the opportunity to determine whether the potential candidate has the desired characteristics, and to give him or her more information about the job (such as the schedule,

salary and other requirements). If, after a brief discussion and assessment, the person with SCI decides to interview the applicant, there are several guidelines that may be helpful when conducting an interview. Keep in mind that it is not uncommon for someone to make an appointment for an interview and then not show. Ask the prospective job candidate to call in advance if he or she has changed their mind about the interview or cannot make the scheduled appointment. The applicant should bring his or her Social Security number, at least two references and a driver's license or state issued identification to the interview.

The Interview

Consider conducting the interview at a location other than your home for safety reasons. If possible, have a friend or relative present or nearby during the interview. In preparation for the interview, have a list of needs and the job description, as well as some issues/questions to discuss with the applicant. Include space to write down your feelings (positive and negative) about the applicant following the interview. The interview should be seen as an opportunity to get to know the prospective assistant. Discuss previous work experience, including length of employment for each position he or she has held. This is an important issue to bring up. You don't want to spend the time training a personal care assistant to have him or her quit after a short time. Inquire about the type of work the applicant has enjoyed most and liked the least, and whether they have experience and are comfortable around a person with a disability.

The applicant's transportation resources should also be discussed. If driving is a requirement for the position, talk about the applicant's driving record and find out if he or she would be comfortable driving your vehicle should that be necessary. Talking about social issues, such as smoking, alcohol and drug use, personal likes and dislikes, and recreation and leisure pursuits, will provide the opportunity for you and the applicant to determine if it is feasible to work together.

The interview process is also the time to discuss the needs of the person with SCI and exactly what the job entails in detail. It may be helpful to use either a job description or needs checklist as a guideline for this discussion. It is especially important to talk about the job's physical requirements, such as lifting, transferring, bathing, etc. After you have described your needs and the job requirements, ask the applicant whether there are any tasks he or she would not feel comfortable performing (such as the bowel program).

Continued on page 7

Sample Personal Needs Assessment

Bathing:

- Type of bath (shower, bed bath, set-up): _____
- Frequency: _____
- Time of day: _____
- Time required: _____

Dressing:

- Level of assistance: _____
- Special considerations: _____
- Time required: _____

Oral Hygiene and Grooming:

- Frequency: _____
- Type of assistance required: _____

Bowel Care:

- Type of bowel program (in bed, on toilet, etc.): _____
- Frequency of bowel care: _____
- Time of day: _____
- Time required: _____

Bladder Care:

- Type of bladder program (intermittent catheter, condom catheter, suprapubic): _____
- Frequency of bladder care: _____
- Time of day: _____
- Time required: _____

Transfers:

- Type of transfer (dependent, sliding board, hydraulic lift, etc.): _____
- Amount of assistance required: _____
- When needed: _____
- Special considerations (shoulder pain, special techniques, etc.): _____

Eating:

- Other than meal preparation, any special help (adaptive equipment; set-up): _____
- Special diet: _____

Medication:

- Type of medications: _____
- Frequency: _____
- Who administers: _____

Exercise Program:

- Type of exercise program (ROM, strengthening, etc.): _____
- Frequency: _____
- How long does exercise program take? _____

Laundry:

- Level of assistance required: _____
- How often: _____
- Where is laundry done? _____

Housecleaning:

- Frequency: _____
- How many rooms need to be cleaned? _____
- Specific chores: _____

Meal Preparation:

- Time of meals: _____
- Who will plan? _____

Grocery Shopping:

- Frequency: _____
- Where is shopping done? _____
- Who is responsible? _____

Travel needs:

- Location: _____
- Frequency, and schedule: _____
- Transportation: _____

Also discuss compensation – whether pay will be hourly or a combination of a stipend with room and board. Let the applicant know the days and hours you need assistance and clarify the days he/she will have off. Ask the applicant why he or she is interested in the job. Finally, finish the interview process by giving the applicant the opportunity to ask you questions about the job requirements or your lifestyle. Discuss your timeline for making a decision and assure him or her that you will get in touch with your choice whether or not they are selected for the position.

Employment References

The next step in the interview process is to contact the applicant's references. It is imperative before hiring anyone to check references. It can sometimes be difficult to get information from previous employers for fear of a lawsuit, but explain your situation clearly, and if a reference refuses to give you information about an applicant, move onto the next reference, or ask the applicant for additional references. The feedback you receive from a previous employer may be the deciding factor in whether you hire someone. During a reference check, try to obtain information on the applicant's length of employment, type of tasks performed in the course of the job, reliability, promptness, response to feedback and supervision, ability to learn new tasks, and why the applicant left the previous job. Finally, ask the former employer whether the applicant would be considered for future employment.

Making a Decision

After you have completed the interview process and obtained information from all of the applicant's references, it is time to make a decision as to who to hire for personal care. An important consideration when making a final selection should be your gut reaction to a potential applicant. Regardless of qualifications, if for any reason, you do not feel completely comfortable with an applicant, do not consider him or her for the position. Consider factors such as how well the applicant's personality, emotional stability, and lifestyle fit with the person with SCI. For example, is the applicant a night owl while the person with SCI likes to get an early start in the morning? Consider the physical as well as the emotional well-being of the applicant. Hiring an emotionally unstable person to provide personal care may be a roller coaster ride. Once a decision has been made, extend the job offer as soon as possible, and let all others know of your decision.

Once the applicant accepts the position, prepare and review the contract. The contract should specify hours of work per day or week, hourly pay, length of notice to be given for vacation, sick notice and termination notice. Once both parties have agreed to the terms of the contract, the agreement should be signed and dated by both.

Continued on page 9

Here is a rating sheet you can use during the interview process to help you evaluate potential caregivers:

Personal Assistant Services Attendant Rating Sheet

Date: _____

Prospective Attendant's Name: _____

Male Female Age: _____

Home Number: _____ Cell Number: _____ Email Address: _____

Overall Impression of Prospective Attendant:

Positive Attributes: _____

Areas of Concern: _____

Physical Requirements:

_____ Good Health

_____ Physical stamina

_____ Hygiene/Cleanliness

Qualities:

_____ Dependability

_____ Learning ability

_____ Intelligence

_____ Attitude

_____ Neat appearance

_____ Honesty

_____ Patience

_____ Punctuality

_____ Compatibility

Capabilities to Look For:

_____ Ability to drive

_____ Cooking and cleaning

_____ Ability to perform personal care

_____ Mechanical abilities

_____ Language

_____ Ability to lift/transfer

References: _____

Experience: _____

Availability: _____

Other Comments: _____

Guidelines for Attendant Training

You will need to teach your newly hired personal care assistant what you need done in terms of your care, and how he or she can best meet your needs. If at all possible, the training process should begin in the hospital before discharge where the expertise of the staff can be used to facilitate the process. Often, however, it is not possible to hire an assistant until after discharge from the hospital or rehabilitation center. It is helpful to use your self-care checklist when training your assistant. The checklist ensures that you have covered all aspects of your care, breaks down each task into manageable steps, and can be used as a written resource for your caregiver in the future. To help your personal care assistant better understand your needs, have a frank discussion about your disability and how it relates to what you can and cannot do for yourself. If the assistant has a good foundation of knowledge about how the bowel and bladder are affected by a spinal cord injury, then as you teach him or her how to perform bowel and bladder care, it will be easier to learn. Encourage your assistant to ask questions throughout the training process and clarify any medical or technical terms as you go along. There are several excellent self-care/education manuals for individuals with SCI that can be used as training tools. See, for example: www.myshepherdconnection.org/sci.

Each personal care task (for example, bathing) should be broken down into smaller, manageable steps. Give the attendant instruction on each step and explain why it is important to you that each step be done the way you request. Remember that repetition is the key to learning, and therefore, it may take your assistant several attempts before he or she performs the task exactly the way you would like. Encourage your attendant to give you feedback

and ask questions. Give positive feedback when your caregiver gets the task right and use humor whenever possible.

Your Relationship with Your Personal Care Assistant

Providing a positive work environment is a key factor in keeping your personal care assistant. Good communication is the key to maintaining any relationship, and your relationship with your caregiver is no exception. It is important to keep communication pathways open. If you sense any problems or misunderstandings with your caregiver, get them out in the open by confronting the issue and discussing it as quickly as possible. To facilitate a positive relationship, you must treat your assistant with respect and be as flexible as possible. Keep in mind that he or she has responsibilities and commitments outside of providing your personal care. Respect his or her privacy and base your relationship on honesty, mutual respect and open communication.

Giving (and receiving) feedback is an important aspect of the relationship between caregiver and employer. When it becomes necessary to give critical feedback, make it as positive and constructive as possible. Although it can be difficult, give the feedback immediately after your caregiver performs the task or exhibits the behavior you are criticizing. Give feedback on only one incident at a time, and provide feedback on the person's actions, not the person. Make sure you use the opportunity to help your assistant do the job more effectively rather than launching a personal attack. After giving critical feedback, be sure to clarify how you would like the task performed or the situation handled in the future.

Continued on page 11

Personal Assistant Services Checklist for Self-Care Activities

Checklist for Bathing

- Get clothes ready
 - Prepare bath water
 - Check bathroom temperature
 - Make sure needed supplies are available
 - Ensure privacy
 - Assist with clothing removal
 - Transfer from bed to bath
 - Wash and rinse body
 - Assist with hair care
 - Transfer from bath to dressing area
 - Dry body thoroughly
 - Inspect skin for pressure sores
 - Apply lotion or powder
 - Apply deodorant and makeup and/or shave
 - Assist with dressing
 - Assist with bladder and bowel care
 - Transfer to wheelchair
 - Assist with dental care
 - Move to breakfast area
 - Put away all supplies
 - Clean bathroom
 - Clean and disinfect bladder and bowel care supplies
- Preparation: _____

- Clean Up: _____

The parties to this agreement are:

1. (Employee), who will be responsible to (employer). Both parties agree to assume the duties and the responsibilities of the employer-employee relationship as described in this agreement.
2. **Place of Employment:** Employee's duties shall be primarily carried out at the employer's residence, but may involve local travel for medical appointments, shopping and similar purposes.
3. **Hours of Employment:** Regular days and hours shall be:

It is understood that these days and/or hours may change. Any permanent change must be noted in writing and initialed by both parties.

4. **Pay Schedule:** Employer agrees to pay employee at the rate of \$__ per hour/day/week/month. Payday will be on the day of the day/week/month. Reimbursement for mileage for use of employee's car shall be at the rate of cents per mile. Payment will be made by cash/check.
5. **Employee Duties:** Employee's duties are for the benefit of the employer only, not for other household members (unless otherwise contracted). The employee shall perform only listed duties on a regular basis.
6. **Supervision:** Supervision and direction of employee shall be the sole responsibility of the employer, unless otherwise agreed to in writing. Special medication shall be under the direction of a physician.
7. **Expertise:** It is understood that the employee has no special medical knowledge or skills unless otherwise stated in advance, and is not responsible for professional nursing service.
8. **Termination:** Either party may terminate this agreement with two weeks' notice in writing. Any wages and/or reimbursement due will be paid on termination if at the instigation of the employer; and on the next regular payday if instigated by the employee.
9. **Vacation/Sick Leave:** Employee will request vacation time (not to exceed two weeks per year) at least two weeks in advance to allow the employer to arrange coverage. In the event the employee is sick, he or she will notify employer at least one hour before the start of the shift, except in the event of an emergency.

Agreement signed on this _____ day of _____, _____.

Employer Signature: _____

Employee Signature: _____

Screening and Interviewing a Prospective Personal Care Assistant

Your style of communication can also be an important factor in maintaining a comfortable working relationship with your caregiver. Using an assertive rather than aggressive style will foster open communication. An assertive person is open to feedback from others, is direct and gives clear messages. The assertive individual is also honest with himself and also with others. Aggressive behavior does not show consideration for the feelings of others and tends to shut down the lines of communication.

Your lifestyle may differ from that of your personal care assistant. You may have differences of opinion over something as minor as which television programs or music you prefer, or over major issues such as smoking, and drug and/or alcohol use. Consider your tolerance level for such behavior and make your stand clear. If you do not want someone to smoke in your home, for example, ask your assistant to smoke outside. Do not allow drinking or drug use to interfere with your caregiver's ability to meet your needs and perform the job.

To provide an optimal working environment for your caregiver and foster a positive relationship, there are several things to keep in mind when you interact. You need to establish your position as employer as soon as possible to ensure that your needs will be met in the manner you would like. However, keep in mind that the job of providing personal care is not easy, and try not to be too demanding.

It is important to be kind and courteous when you ask for assistance. When communicating your needs, try putting yourself in your caregiver's place, and think about how you would want someone to talk to you. It is upsetting to be taken for granted, so try to show your appreciation by thanking your assistant. Being organized will benefit you, as well as your attendant. Make a list of the tasks you need to have done each day of the week. This makes the best use of the time you have with your caregiver and forces you to anticipate your future needs in terms of daily activities and errands.

Think about things like grocery and errand needs – which day you plan on shopping and when. Do you need assistance with your laundry and when does it need to be done? Are you able to do your bowel program in the evening so as to lighten up the morning activities? When you organize your needs and prepare for the week, you communicate respect for your attendant's time, and both of you are likely to get more done with the time you have together.

Unfortunately, it is possible that the person you selected to be your caregiver may not actually be a good match for you or is unable to meet your needs. If this is the case, it is always preferable to part ways on the best possible terms, as you may want to use your assistant as a back-up caregiver in the future (if circumstances allow). Make sure your house key and any other personal effects are returned. Get

a forwarding address and other contact information, if possible, in case you need to contact him or her in the future.

Funding Issues and Resources

There are programs that provide funds to help pay for attendant care. Participation in such programs depends on specific eligibility requirements that vary from area to area. It is important to meet with a social worker, case manager, independent living advocate, or other professional to discuss your specific needs and whether you may be eligible to receive funds.

Keep in mind that most programs only provide minimum wage for personal care assistants, and it is difficult to find and retain a personal care assistant for minimum wage because of the nature of the work. Consider supplementing the minimum wage with additional money to pay your attendant a salary comparable to the going rate in the area. If this is not possible, consider providing other benefits such as room and board, in addition to the cash wage.

Listed below are possible resources to explore for funding personal care:

Private Resources

1. Health Insurance
2. Auto Insurance
3. Worker's Compensation

Public Resources

4. Medicaid (Department of Social and Health Services)
5. Department of Vocational Rehabilitation
6. Department of Veterans Affairs (if you are a veteran)
7. Crime Victims Compensation
8. Other state-funded programs, including Medicaid waiver programs

Medicaid Waiver Programs

There are three waiver programs available in Georgia to Medicaid recipients. The programs are Community Care Services Provider (CCSP), Independent Care Waiver Program (ICWP) and SOURCE.

You can only be accepted by ONE of these three programs at a time. Once you are officially enrolled in Medicaid and have a good idea what your care needs will be, you can contact these programs to be evaluated and find out if you qualify for the services they provide.

Often, you will be advised to wait until you are out of the hospital to be assessed so that the programs can get an accurate picture of your needs. You are being given this information now so you are aware of the services and may contact them with any questions.

Personal Assistant Services Attendant Timesheet

It is important (and a requirement for most funding sources) to keep a record of the hours your personal care assistant works. This is best done by keeping a timesheet.

Sample timesheet:

Time In: _____

Date, including year: _____

Time Out: _____

Hours Worked: _____

Responsibilities as an Employer:

Also, as an employer, you are responsible for paying Social Security and other employer taxes. See the IRS web site at www.irs.gov. If you are self-paying for home care service employee(s), you will need to apply for an employer's tax ID number (W-9) from the IRS. The IRS gives details on your responsibilities as an employer of a PCA on their website here:

www.irs.gov/Businesses/Small-Businesses-&Self-Employed/Businesses-with-Employees

If you are receiving funds from an outside source to pay for attendant services, follow the agency's guidelines regarding the records you need to keep, how your attendant will be paid, and the taxes you are responsible for withholding and paying. Whether your caregiver is terminated or leaves for his or her own reasons, you will once again need to start the process of finding someone to provide your care. It is preferable to start this process while your attendant is still with you. However, this is not always possible, as many times, the caregiver leaves with little or no notice. This is why it is important to have back-up care in place. Hopefully, the knowledge gained through the experience of hiring and managing your first attendant will make the process of finding a replacement caregiver easier.

Personal Care/Caregiver Resources

› Caregiver Action Network

<http://caregiveraction.org/about/>

The Caregiver Action Network is the nation's leading family caregiver organization working to improve the quality of life for the than 65 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with special needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer's disease. CAN (formerly the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

› Family Caregiver Alliance

www.caregiver.org/caregiver/jsp/home.jsp

Founded in 1977, Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. Long recognized as a pioneer in health services, FCA now offers programs at national, state and local levels to support and sustain caregivers.

› University of Alabama at Birmingham, Spinal Cord Injury Information Network

www.uab.edu/medicine/sci/daily-living/caregiving

A number of information sheets are available on topics, including caregiving, hiring caregivers and caregiver burnout.

› University of Minnesota

www.ildspinitiative.com/docs/ToolkitforFamilies.pdf

Find, Choose, and Keep Great Direct Support Professionals is a downloadable comprehensive model and guide for selecting a personal caretaker.

General SCI Resources

› American Spinal Injury Association

www.asia-spinalinjury.org

Information on the standard SCI classification scale, new research in the field of SCI and links to other SCI resources

› Brain and Spinal Injury Trust Fund Commission

www.gatrustfund.org

Provides information on state resources available to residents of Georgia who have an SCI

› Christopher and Dana Reeve Foundation

www.christopherreeve.org

Focused first on raising research funding for SCI treatment, the Christopher and Dana Reeve Foundation also seeks to improve the quality of life for people living with paralysis through grants, information and advocacy.

› Facing Disability Online

www.facingdisability.com/

A great SCI resource, including many educational videos; largely focused toward providing a peer-support community

› National Library of Medicine and the National Institutes of Health

www.nlm.nih.gov/medlineplus/spinalcordinjuries.html#cat29

Provides a variety of technical medical resources; many SCI-related handouts available in Spanish

› National Spinal Cord Injury Association (NSCIA)

www.spinalcord.org/resource-center/#

A comprehensive SCI-related website; features a large archive of webinar videos on SCI topics

› Paralyzed Veterans of America

www.pva.org

The website focuses primarily on injured veterans; however, the information on disability rights, sports and recreation applies to veterans and non-veterans alike.

Continued on next page

General SCI Resources

➤ Shepherd Center

www.shepherd.org

Specializing in spinal cord injury treatment, the Center offers patient, family, and medical professionals a variety of SCI-related information.

➤ SPINALpedia

SPINALpedia.com

A social mentoring network and video archive, SPINALpedia.com allows members of the SCI community to motivate each other by sharing their stories and experiences.

➤ University of Alabama at Birmingham

www.uab.edu/medicine/sci/

This website is a information network to promote knowledge in the areas of research, health and quality of life for people with spinal cord injuries, their families and SCI-related professionals.

➤ United Spinal Association

www.unitedspinal.org/

United Spinal Association is a long-established advocacy group for the SCI community. The website includes up-to-date policy news affecting the SCI community.

Developed and Created by Shepherd Center.

Design by Edward Tharp

Copyright © 2013 by Shepherd Center. All Rights Reserved. No part of this publication may be reproduced without the prior, written permission of Shepherd Center.

Shepherd Center, located in Atlanta, Ga., is a private, not-for-profit hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury or brain injury. Founded in 1975, Shepherd Center is ranked by *U.S. News & World Report* among the top 10 rehabilitation hospitals in the nation and is a 152-bed facility. For more information, visit Shepherd Center online at shepherd.org.