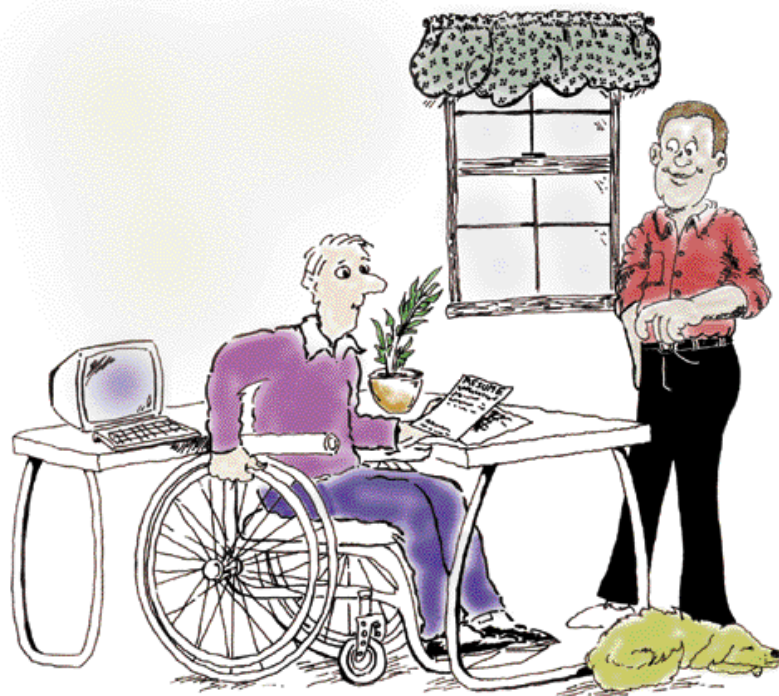


Managing Personal Assistants

a consumer guide

Featuring:

- RECRUITING, HIRING, TRAINING, KEEPING, AND FIRING PERSONAL ASSISTANTS
- FUNDING SOURCES
- TAX INFORMATION
- FORMS



Managing Personal Assistants: *A Consumer Guide*

This guide contains general advice to those seeking personal care assistance in their home. It is not an authoritative legal treatise and should not be relied upon as authority for acting or failing to act. Readers may wish to consult a tax specialist or attorney with specific questions.

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Acknowledgments

This project has been both a labor of love and a commitment to people with disabilities everywhere. This manual addresses a missing piece of significant support and skill training for many members of the Paralyzed Veterans of America (PVA) and their families: information that would help them establish and maintain their own personal assistance services (PAS) system, designed to fit the needs of each individual. It rapidly became obvious that many of the issues faced by PVA members are also faced by other people with disabilities throughout the United States.

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Welcome

Personal assistance services (PAS) for a person with a disability can make the difference between living a full and productive life or merely existing. This manual has been designed to help you, your family, and friends develop and manage a personal assistance services system to meet your individual needs.

For more than 50 years, the Paralyzed Veterans of America has been a strong advocate for people with spinal cord injury or disease, and indeed all people with disabilities. Increasingly, it has become evident that many people requiring help with activities of daily living (ADLs) could benefit from training in how to recruit, hire, and manage personal assistants. Very few programs teach these skills—and those usually require that the person with a disability attend formal classes.

This manual has been designed as a “how to” book for a person with a disability to learn, at your own pace and on your own schedule, the skills to establish and keep a personal assistance services system. The only test is how well you are able to manage your own system.

Think about the issues the manual raises as you assess your needs and your preferences for the kind of person who will be sharing some very personal aspects of your life. The more fully you use the ideas in the manual and practice the skills it suggests, the more effective your personal assistance services system will be.

This manual will also be useful to family and friends of people with disabilities—especially those whose loved one may be unable or unwilling to manage a PAS system for themselves.

Finally, it is for the many people who will need a personal assistant for a short period of time. This manual can be helpful in setting up a temporary system during a recovery or rehabilitation period.

Managing a PAS system is like running your own small business. Most of us receive some level of on-the-job training to do our work, but there aren't many opportunities to learn the skills it takes to handle our own PAS needs. Therefore, we've created a comprehensive guide. The clearly identified sections allow you to use any or all parts of the manual. For example, you may already know how to interview a prospective employee. If that's the

case, feel free to move ahead to the next section. We do suggest, however, that you at least skim through those chapters covering the skills you already have. There may be some useful information for you—a helpful tip, a reminder of something you've let slip, or validation that you're doing the right thing.

MANAGING A PAS SYSTEM IS LIKE RUNNING YOUR OWN SMALL BUSINESS

This manual is based on the belief that no one is better qualified to run a PAS system than the user of the services—you. We strongly believe that you can and should be in control of your life—and the use of a personal assistance system can be one of the most important factors contributing to your independence.

The consumers who are the most successful PAS managers have several things in common:

- They are straightforward but polite in communicating their needs.
- They pay attention to important details.
- They follow logical, sensible rules for controlling their lives and their environments.
- They are flexible in their schedule and their attitude.

This manual presents these basic but essential skills in a way that you can learn them and use them successfully in your home. Also, you may wish to have your spouse, family, and/or friends be a part of the learning process.

We have included some examples of forms that you may find useful in managing a PAS system (see the appendix). If these forms work for you, you are welcome to make as many copies of them as you need. If you wish to use the ideas from the forms to develop your own version, you may make revisions, additions, or deletions to fit your needs.

We also want to make clear what this manual is not:

1. **It is not a medical text.** Your health is a matter between you, your family, and your health-care professionals. Be sure to seek medical advice from your physician.
2. **It is not a tax manual.** Your income taxes are your business. The manual points out some of your obligations as an employer, but it is up to you to handle all tax matters with advisors of your choice.

NO ONE IS BETTER QUALIFIED TO RUN A PAS SYSTEM THAN THE USER OF THE SERVICES—YOU

3. **It is not a legal manual.** The manual points out some of the legal issues that can arise for you as an employer, but it is not a substitute for professional counsel. You should check your homeowner's or renters insurance policy (or consult your insurance agent) to make sure that either workers' compensa-

tion statutes or your insurance covers a personal assistant for any injuries. There may be gaps where you have personal liability exposure. You should seek advice from an attorney on specific legal matters.

4. **It is not the "only" way to handle a PAS system.** Using the information, suggestions, and forms can help you to gain the skills you need, but there are other successful ways to manage a PAS system. What works best for you is the best system for you.

When hiring and managing your own personal assistants, please keep in mind that, for most people, being a personal assistant is seldom a career goal. The hours are often long or unsteady, the salary is low compared to full-time employment salaries, and there are seldom significant benefits such as health insurance, paid vacations, or retirement programs. Personal assistants need

careful and thoughtful interaction and supervision to be certain they get the more intangible benefits—positive feedback, respect, dignity, and considerate treatment—to give them the necessary job satisfaction and maintain their motivation to stay in the field.

Assessing Your Needs

A personal assistant (sometimes called a home health aide or personal care attendant) is a person who provides assistance with the activities of daily living (ADLs) and instrumental activities of daily living (IADLs) to other individuals. Examples of such services include bathing, skin inspection, dressing, meal preparation, light house-keeping, laundry, transferring (for example, from a wheelchair to bed), and bowel and bladder care. These are activities required for day-to-day functioning and safety that the person receiving the service is unable to perform independently due to illness or injury.

Who Uses Personal Assistants

Personal assistant services (PAS) are used by a large variety of people, including many who are paralyzed from spinal cord injury or disease. A growing number of people using personal assistance services are elderly or chronically ill. People also may require personal assistance on a temporary basis while recovering from an illness or injury. Personal assistants make it possible for people who need some help with activities of daily living to remain out of a hospital or nursing home, live in their own homes, and stay independent and active.

Estimates of the number of people in the United States who require some level of assistance with their activities of daily living range from 4 million to more than 12 million. The level of assistance needed can range from simple help with cooking and cleaning for an elderly person to full-time care for someone completely disabled from multiple sclerosis or paralysis from a spinal cord injury.

While a substantial amount of personal assistance is provided by family members (such as parents or spouses), millions of people prefer to have the necessary services furnished by someone hired specifically for that purpose, for a number of reasons. When a spouse acts as a personal assistant, the marital relationship can be changed dramatically and intimacy can suffer. Also, as people age their physical abilities may change, and it may become more difficult, for example, to help a spouse or child with transfers. For the user of personal assistance services, it is often easier to give instructions to an employee than to a family member.

Defining Your Personal Assistance Needs

If you believe that you need the services of a personal assistant, you should begin to think about the type of services that you will need. Preparing lists can be a useful way to put your thoughts in order and to define specific needs.

Start to assess your needs by considering exactly what type of tasks you need assistance with (such as bathing, dressing, bowel and bladder care, transferring, transportation, meal preparation). Make a list of all of the needs that you may have. The Sample Needs Assessment Worksheet will help you begin. You will want to add items of your own to have a complete list. (There is another copy in the appendix that you can copy and use or modify to meet your needs.)

There are generally three types of needs for which you may need assistance:

- activities of daily living (ADLs), which involve direct personal care, such as bathing, dressing, eating, bowel and bladder care
- instrumental activities of daily living (IADLs), which involve indirect care needs, such as cleaning, doing laundry, buying groceries, driving
- medical-related functions, that require some degree of health-care training, such as managing medications

Thinking about your needs in these three areas may help you to develop a comprehensive needs assessment.

When you have defined your needs by listing them, you now must decide how often and when you need help with each task (morning and evening, once daily, weekly, etc.). You should also estimate how much time is required for each task.

Try to group tasks together in the same time frame to reduce the hours of help required. For example, can a personal assistant who helps you dress in the morning also prepare lunch and leave it in the refrigerator for you? Can the same morning assistant set up your bedroom so that you can perform your evening routine without assistance?

SERVICE ANIMALS

You may find that the tasks you need assistance with could be performed by a service animal or canine companion. Tasks that require mainly strength or agility (picking up dropped items, propelling a wheelchair, opening and closing doors, carrying items, pulling off socks) can be performed by trained animals. As you assess your needs, think about who could perform the services you need, whether those that actually require a human touch can be combined into one or two time periods a day, and if those that occur intermittently throughout the day could be done by a service animal.

There are psychological and financial benefits to relying on animal (usually canine) rather than human helpers. Many people who have service animals find a great increase in their independence and quality of life. The dog is both a willing partner and helper and an enthusiastic, affectionate companion. Many of the issues that arise with a human personal assistant do not apply with dogs, such as maintaining the role of the employer while accepting personal services. The dog will be very happy to be the dog while you remain the master.

Many service animal organizations exist all over the country; check your local phone book. A few organizations include:

- **Assistance Dog Institute**
(707) 585-0300, www.assistedog.org
- **Canine Companions for Independence**
(800) 572-2275,
www.caninecompanions.org
- **Canine Partners for Life**
(610) 869-4902, www.k94life.org
- **Helping Hands: Monkey Helpers for the Disabled**
(617) 787-4419,
www.helpinghandsmonkeys.org
- **Delta Society**
(800) 869-6898, www.deltasociety.org

The more you can consolidate tasks—and assume responsibility for doing as many of the tasks yourself as you can—the less dependent you will be on an assistant (and the less you will have to pay). Talk to someone who knows your routine and care needs (family, friend, or someone who is already providing some services for you) to help you double check your list and make sure you have included everything you need.

Next, list your general “people” preferences. The Sample Consumer Preferences Work Sheet will help you begin. You will want to add items of your own to have a complete list. (There is another copy in the appendix that you can copy and use or modify to meet your needs.)

You can make notes of why particular items are important to you, so applicants will know that you’re being reasonable and not arbitrary. We’ve also included a sample of such a work sheet as it might be filled in by someone doing this type of assessment. You will have different preferences, probably. But this will help you start thinking about the kind of issues that might arise.

This work sheet will help you list and organize your preferences when you are preparing to employ a personal assistant. It is unlikely that there will be an absolutely perfect match because you are, after all, dealing with human beings. There are some areas where you might be willing to compromise but others where you feel you cannot. It is important that you know and are able to clearly identify these areas for yourself and others. The worksheet helps you do that by suggesting three categories to use to rate your needs:

- **Absolutely Essential** means you risk a serious problem if you accept a person who doesn’t fulfill that important personal preference. It is probably not something on which you can compromise safely.
- **Very Important** means it will be hard to get along without that quality—compromise will be difficult, but possible.
- **Would Be Nice** means you can easily compromise.

If your personal assistant will be living with you, you should also think about your preferences for someone who will be sharing your home. Use the Sample Live-In Assistant Preferences Work Sheet to identify those things you like and dislike about a person you share your home with. If you have ever lived in a dormitory situation or had a roommate, you can think back to some of the issues or problems that were raised from living with another person. As with the other work sheets, you should include not just the items listed but those that relate to your specific situation.

Sample Needs Assessment Work Sheet

Need	Frequency	Time Needed	AM	PM
ADLs				
Bathing				
Dressing				
Grooming (shaving, hair care, makeup)				
Meal preparation				
Eating				
Bowel care				
Bladder care				
Turning in bed				
Transferring				
Other:				
IADLs				
Washing dishes				
Grocery shopping				
Turning on computer				
Setting up equipment				
Making bed				
Charging wheelchair batteries				
Driving van				
Errands				
Writing letters				
Answering phone				
Laundry				
Putting away items				
Housecleaning				
Child care				
Pet care				
Other:				
Medical-Related Care				
Pressure relief/positioning				
Medications				
Range of motion exercises				
Skin inspection				
Suctioning, respiratory care				
Other:				

ASSISTIVE TECHNOLOGY

Assistive technology (AT) can increase your independence and decrease your reliance on personal assistants. Assistive technology includes a wide variety of devices, some very simple such as a long straw or a “grabber,” others complex and large, such as automatic door openers, remote controls, electric beds, and environmental control units. Any device that helps you to live your life more independently qualifies as AT. Just remember, AT does not have to be electronic or expensive, it just needs to help you do what you want to do.

The Technology Related Assistance Act for Individuals with Disabilities of 1988, as amended (Public Law 103-218) (the Tech Act) works to reduce barriers to the availability, acquisition, and use of assistive technology devices and services for individuals with disabilities within their states. There are programs, usually called Tech Act Projects, in each of the 50 states, plus the District of Columbia, Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

These Tech Act Projects focus their efforts on changing education, vocational rehabilitation systems, medical assistance programs, and others that deliver services to individuals with disabilities. Some activities of state Tech Act Projects include the following:

- Reach out to elderly, rural, and other underrepresented populations to make sure that these groups have greater access to AT
- Operate regional resource centers that often have equipment for demonstration and loan
- Provide information on AT funding and other topics
- Operate equipment loan, equipment exchange, and equipment recycling programs
- Train individuals with disabilities, service providers, and others on topics such as funding and self-advocacy

Through its Technical Assistance Project, the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) serves as a clearinghouse for information on state Tech Act Projects. RESNA can provide a list of contacts including phone, fax, and TTY numbers, as well as street, email, and home page addresses. You can contact RESNA at:

(703) 524-6686, fax (703) 524-6630

TTY (703) 524-6639

www.resna.org/taproject/statecontacts.htm

We've also included a sample of how someone might complete this worksheet. There is another copy in the appendix for you to copy and use or modify to meet your needs.

When you've completed this exercise, you'll have a much more concrete picture of the kind of personal assistant you really want. Remember, the goal is to have an ongoing, long-term relationship with this person and it is critical that you hire someone who fits your unique needs and preferences.

Preparing the Job Description

Now that you have assessed your needs, planned your daily schedule, and identified the type of person you are looking for, it is time to prepare the job description. This is a vital document. It clearly describes what is expected of a potential employee.

The job description must be based on your needs and should include the following information:

- Duties and responsibilities as they apply to your care. Be as specific as possible (for example, does “light housekeeping” mean putting away clutter or scrubbing the bathroom?)
- Number of hours of work per week (paid overtime)
- Scheduled days and times
- Holiday policy (days off paid)
- Salary and benefits
- Qualifications of assistants, such as ability to lift, first aid and CPR training, driver's license

If the assistant is going to live with you, then your job description should also specify expectations of the living arrangement:

- How much of the compensation is room and board versus a salary
- Work hours versus leisure hours
- Days off

- Expectations regarding sharing of common space and personal items
- Roles and rights of other members of the household
- Policy on your and the assistant's visitors
- Use of kitchen and laundry facilities
- Housekeeping
- Acceptable behaviors (smoking, drinking alcohol, partying, etc.)
- How the utility and phone bills will be paid; for example, you and the personal assistant will divide the cost or you will pay for the cost.

You should be specific in your job description so that you avoid an uncomfortable situation and so that anyone applying for the position knows what you need and expect.

A Sample Personal Assistant Job Description is included below and in the appendix. You will want to tailor the job description based on your own needs assessment; this example will help you get started.

Sample Personal Assistant Job Description

Summary of Work:

The personal assistant will provide valuable supportive services to a person with physical disabilities.

Qualifications:

- Must be dependable, drug and alcohol free, and able to follow directions
- Must have current immunizations, TB test, and hepatitis B vaccine
- Should have basic first aid training and CPR certification
- Should be able to lift 100 pounds
- Must have a state driver's license
- Must have a Social Security number or a permit to work in this country

Duties:

The duties of this job include but are not limited to:

- Personal care services such as bathing, skin care, shampoo, grooming, caring for the teeth, helping in and out of bed, and assistance with medications
- Assistance with bowel and bladder care by performing catheterization, emptying catheter, and changing colostomy drainage bags
- Assistance with transfers, range of motion exercises, and other activities to increase muscle strength, self-care, and independence
- Housekeeping (vacuuming, cleaning bathroom, making bed, etc.)
- Shopping, grocery and personal
- Driving on occasion
- Participation in in-service education programs on aspects of the disability of the employer
- Animal care

Schedule:

Be available to work Monday through Friday 7:00 to 9:30 a.m. and 6:30 to 9:00 p.m. Occasional work on weekends may be required.

Salary

\$6.00–\$8.00 per hour, depending on qualifications and experience. Room and board available.

Sample Consumer Preferences Work Sheet

Preference	Absolutely Essential	Very Important	Would Be Nice
Morning person			
Night person			
Able to lift			
Always on time			
Male			
Female			
Nonsmoker			
Nondrinker			
Older person			
Younger person			
Good cook			
Computer literate			
Veteran			
Primary language (English, Spanish, etc.)			
Animal lover			
Drives own car			
Sense of humor			

Sample Live-In Assistant Preferences Work Sheet

Preference	Absolutely Essential	Very Important	Would Be Nice
Temperature comfort range			
Degree of neatness			
Taste in music			
Television viewing			
Talkativeness, energy level			
Amount of companionship			
Telephone use			
Kitchen use			
Laundry use			
Visitors, family, friends			
Pets			
Drug/alcohol use			
Shared expenses			
Car usage			

Sample Completed Consumer Preferences Work Sheet

Preference	Absolutely Essential	Very Important	Would Be Nice
Morning person		most care needed in A.M.	
Night person		-----	-----
Able to lift	165 lbs		
Always on time	X		
Male	NO		
Female	X		
Nonsmoker	X		
Nondrinker		X	
Older person	-----	-----	-----
Younger person			X
Good cook			X
Computer literate			X
Veteran		To help with VA forms	
Primary language (English, Spanish, etc.)	English, my hearing loss makes accents hard to understand		
Animal lover		will help care for Rover	
Drives own car		X	
Sense of humor	X		

Sample Completed Live-In Assistant Preferences Work Sheet

Preference	Absolutely Essential	Very Important	Would Be Nice
Temperature comfort range		70 house	
Degree of neatness	no clutter, no dust—allergies		
Taste in music		No Rap	
Television viewing			Sports Fan
Talkativeness, energy level	calm and quiet after 10 P.M.		
Amount of companionship	some time alone daily		Occasional games, etc...
Telephone use			2nd line possible
Kitchen use			Shared Meals?
Laundry use	perfume sensitivity		
Visitors, family, friends		No one after 10 P.M.	
Pets	Only if compatible with Rover		
Drug/alcohol use	not in my home		
Shared expenses	long distance calls	2nd cable hook up	2nd Phone line
Car usage	van off limits		

Funding Sources

Having determined your personal assistance needs, you must now determine how you are going to pay for them. Hiring personal assistants can be expensive, especially if you require services on a daily basis.

There are programs that may pay for attendant care. Each has its own eligibility criteria, application procedures, and employer responsibilities. A social worker or other member of your health-care team can help you identify resources for which you may be eligible. Hospital social work departments or patient advocates are also good sources of information. You may need to provide such documentation as proof of medical need and information on assets and income.

To get funding from some agencies, it may be necessary to prove you were denied funding from another. Be sure to keep copies of all applications you file and get any denials in writing.

You may have to try many different sources to obtain funding assistance. Perseverance is important.

Sources of Financial Aid

Medicare

Medicare is a national health insurance program for people over 65, people with disabilities, and people with end-stage kidney disease. In general, the following people are eligible:

- Anyone over 65 who is eligible for Social Security or Railroad Retirement Benefits
- People with disabilities who have received Social Security Disability Income for at least 24 months
- Some people who are receiving regular dialysis or have received a kidney transplant because of kidney failure

Medicare Part A covers hospital benefits, skilled nursing facility benefits, hospice benefits, and home health benefits. To be eligible for Medicare home health, a beneficiary must be confined to the home, be under the care of a physician who establishes a plan of care that is reviewed periodically, and need at least one of the following: intermittent skilled nursing care, physical therapy, speech therapy, or continuing occupational therapy.

Skilled nursing care includes the administration of medication, tube feedings, catheter changes, and wound care. It must be administered by a Medicare-certified home health agency (CHHA) in order to be covered.

Note that the eligibility criteria for these services have been tightened recently and the Medicare definition of “homebound” has been controversial.

MONEY IS NOT THE ONLY WAY TO PAY FOR ASSISTANT SERVICES

While Medicare will not cover chores, housekeeping, and other services from a personal assistant (your ADLs and IADLs), you may be able to have the CHHA perform your medical-related care, reducing the duties of and skills needed by your personal assistant.

Medicaid

Medicaid is a federal and state partnership that provides health and long-term care services for low-income individuals. States must offer home health services to all beneficiaries who are entitled to nursing facility services. A physician must order the services and they must be provided by a home health agency. Some personal care may be included as home health services.

In addition, many state Medicaid programs have requested and received a federal waiver from the Health Care Financing Administration, the federal agency that oversees Medicaid, to provide personal assistance services. Many of these state Medicaid programs offer only limited personal assistance service benefits and have waiting lists of people who want to receive those benefits. However, they are often the only program available, so it would be worth your while to get on the list.

Contact your state Medicaid office to find out if your state has a Medicaid waiver and a program that provides personal assistance services.

Individual State Funded Personal Assistance Programs.

A few states have created special programs to provide personal assistance services for their residents. These small programs are generally funded by state government and have long waiting lists for services. A call to your state Department of Vocational Rehabilitation, state or

LOOKING FOR FINANCIAL AID

The policies and programs of each state and county vary, including what they are called. If you don't know the name of the office or program that can help you, how can you call them? As the telephone company used to advertise, let your fingers do the walking.

In the telephone book, in addition to the white pages (residential and business numbers) and the yellow pages (business advertising) there are the blue pages. The blue pages list local, county (or parish), state, federal, and regional government offices.

Look for agencies with any of the following titles:

- Human Services Department
- Social Services Department
- Family Services Department
- In-Home Support Services
- Office for Physically Disabled Persons
- Adult Services
- Disability Services Board
- Long-Term Care Ombudsman Program
- Department of Health
- Developmental Disabilities Desk
- Disability Rights
- Department of Vocational Rehabilitation
- Office of Employment
- Rehabilitative Services

In the white business pages, look for United Way Referral and Information, Elder Care, and Older Americans Act. On the Internet, try www.eldernet.com

You may need plenty of patience in your search. Ask if the office or agency deals with personal assistance (or in-home support services). If that agency does not, ask who does. It may take many tries until you find the right office, but keep at it. Help is out there!

county Human Services Department, or Center for Independent Living should put you in touch with these programs.

Insurance coverage

Some private insurance policies will pay for attendant care. Health maintenance organizations (HMOs) may have a special needs consumer division. You can call and ask for that division or the office of the HMO's ombudsman.

Department of Veterans Affairs

If you are a veteran you can apply for aide and attendant services through your local Department of Veterans Affairs Office.

Vocational Rehabilitation

If you are in vocational rehabilitation, they may be able to help you pay for some assistant care.

Non-Cash Options

Money is not the only way to pay for personal assistant services. Exchanges of services or other noncash wages are common to either partially or totally offset a salary. (Be aware that in-kind or noncash compensation may be taxable under both federal and some state tax codes.) Some noncash options for obtaining personal assistant services include the following:

- Offer room and board with a reduced salary.
- Utilize your expertise and exchange services. For example, offer English lessons if the personal assistant is new to the country. Offer access to your home computer and lessons on using it. Barter your time and talents in return for the services you need.
- Family and friends. Many people have family members or friends who provide services, although this should be your last resort, used in an emergency.

There are options available to fund assistant services. You are limited only by your imagination. Be creative and use your resources well.

Recruiting a Personal Assistant

You have several places to look for a personal assistant (PA). Each option has its pros and cons. Knowing these, however, makes it possible to prepare in advance and overcome potential obstacles. The most frequently used sources are:

- Centers for Independent Living
- Senior centers, agencies on aging
- Your doctor's office or other health-care facility
- Nursing schools
- State Department of Developmental Disability or county Vocational Rehabilitation
- A home health-care agency
- Refugee agencies
- Placing an ad in the local newspaper or classified advertising magazine
- Posting flyers on bulletin boards (in schools, community centers, community colleges, places of worship, supermarkets, etc.)
- Word of mouth (let your neighbors, friends, family know that you are looking for a personal assistant)

Most urban areas are served by a Center for Independent Living—a CIL (pronounced “sill”). These organizations are organized as part of a national group of similar organizations, the National Council on Independent Living. Centers for Independent Living often provide training on how to manage employees, search for an assistant, and other issues about which you may need more information. CILs assist people with disabilities to live independently and many CILs maintain an information and referral service for personal assistants. CILs do not guarantee the quality of the people on the list—it is always your responsibility to do your own reference checking. However, CILs are an excellent source of information about assistants as well as support groups, legal matters, housing, and many other items that may be of special interest to you. Contact: 1916 Wilson Boulevard, Suite 209, Arlington, VA 22201, (703) 525-3406 voice, (703) 525-4153 TTY, (703) 525-3409 fax, www.ncil.org website, ncil@tsbbs08.tnet.com email.

In rural areas, similar services are provided by programs for rural independent living, contact the Association of Programs for Rural Independent Living, 5903 Powdermill Road, Kent, Ohio 44240, (330) 678-7648 voice, (330) 678-7658 fax, ruralinstitute.umt.edu/APRIL website, LGONZ21800@aol.com email.

Senior centers often maintain lists of people willing and able to do attendant work. Your physician, rehabilitation doctor, social worker, or other medical staff may have information or lists of people to contact regarding attendant care. These sources will provide initial leads, but do not guarantee the quality of the people on the list.

Nursing schools may be able to help you locate nursing students who want to gain experience in the skills of their future profession. They are most likely to view your care needs seriously and not see home health care as “babysitting.” Issues with students often involve schedules and the competing demands on their times.

ROOM NEAR CAMPUS IN EXCHANGE FOR WORK

Available to a quiet, reliable person able to assist a disabled woman with personal care and light housekeeping.

TWO POSITIONS AVAILABLE:

- (1) Monday through Friday,
- (2) Saturday and Sunday.

Two hours per day (evenings).

Nonsmoker preferred, no drugs or alcohol.
References required.

WRITE TO:
P.O. BOX 123
ANYCITY, USA 00000
FOR DETAILS

The state Department of Developmental Disability or Vocational Rehabilitation (the names differ from state to state) provides services to people with developmental disabilities. Depending on your job requirements, some individuals with developmental disabilities can do an excellent job as personal assistants.

You can always use a home health-care agency to find a personal assistant. The personal assistants provided by health-care agencies usually have more training than those who are not associated with these agencies. Also, if a PA quits or does not show up one day, the agency will provide a replacement and you may not need to screen additional applicants for temporary needs. Agencies provide insurance and other benefits to their employees, contributing to a more stable work force.

There are some disadvantages to using an agency. Health-care agencies are often more expensive to use than finding an assistant on your own. They often choose the personal assistant, and while you can indicate a preference, you may not have the option of choosing one for yourself. Also, the agency may have company rules and guidelines that will not allow the personal assistant to take care of your special circumstances.

Refugee agencies can be good sources. As part of the benefit package, you can offer some training in speaking English. Sometimes the agency can offer additional support.

Placing an advertisement in the local newspaper may elicit many responses; however, you will probably need to screen responses from many people who are not qualified for the job. **Safety is also a major issue with advertising. Be especially careful not to put any information in the ad, such as your address, that will make you vulnerable.** You may want to consider using a post office box for responses rather than your telephone number.

Posting flyers on bulletin boards can have the same pros and cons as newspaper advertisements, depending on where the bulletin boards are located. If you post an advertisement on a college campus, you will probably find students who are goal oriented, intelligent, and willing to learn; however, you should expect a high turnover rate due to school vacations, graduations, and school transfers. In many ways, the community college may be a better source for employees than the four-year institutions, because the students are more likely to be local residents, perhaps more permanent, and many will be available year-round—not just when classes are in session.

Word of mouth is a powerful, but often overlooked, recruiting method. It has the benefit of getting leads from people who can tell you about reliable and dependable individuals who have the ability to provide care for you. However, it may be that your network of family and friends will not be able to identify an appropriate personal assistant. Also, if a friend or family member does make a recommendation and you decide not to hire the recommended individual, you may offend the person who made the recommendation.

Finally, don't overlook other people with disabilities. For example, many people with mental retardation are competent, reliable personal assistants. Your state vocational rehabilitation center or local CIL would be a good resource. People with complementary disabilities—each with strengths that offset the other's weaknesses—can provide each other personal assistant services. For example, of two individuals with cerebral palsy, one may have better control of the extremities than the other but have much more difficulty communicating. The one with extremity control assists with clothing and feeding the other, who provides help with communication. Each gives and receives benefits from the arrangement.

NURSING STUDENTS: PRACTICE YOUR SKILLS AND EARN MONEY

Stable and dependable person wanted
to assist a disabled man with personal
care and light housekeeping.

Monday through Friday.
Three hours in the evening.
\$8.00 per hour.

References required, prefer driver's license.

**WRITE TO:
P.O. BOX 123
ANYCITY, USA 00000
FOR DETAILS**

Advertising

When preparing an advertisement consider including the following key elements:

- An eye-catching heading (appeals to the applicant)
- A brief, but clear, description of the job
- Salary and benefits
- A telephone number to call or post office box where applications should be sent

You may also want to include your gender in the advertisement, in order to eliminate applicants who may be uncomfortable caring for a person of the opposite sex. Due to anti-discrimination laws, you cannot advertise for a particular sex, age, race, etc.

Most importantly, you should **never list your home address in the advertisement** for your own safety. It is best not to have the initial interview with applicants at your residence. You may want to meet applicants at a local coffee shop or restaurant.

Handling Responses

When applicants first contact you, pay attention to what they ask first. Do they ask what they would be doing for you? Or do they first ask about pay and time off? This will give you a hint about their priorities.

Whatever they ask, tell them about the specifics of the job. Many people do not understand what is required in giving personal care, such as doing transfers or bladder and bowel care. You may be uncomfortable talking about intimate details to total strangers. However, this telephone call is your first opportunity to establish your relationship with your future personal assistant. The sample Telephone Screening Form that follows will give you an idea of what questions you should ask applicants.

You must be able to describe matter-of-factly the services you need. Use specific, clinical, terms that accurately describe what must be done. ("My assistant will need to change my colostomy bag once a day. Would you mind doing this?" "I use intermittent catheterization for bladder care. Are you familiar with this procedure?")

If the applicant is still interested, ask further questions. If there are essential qualifications (for example, cooking ability, a driver's license, or ability to lift at least a certain weight), find that out. There is no point in wasting your time or the applicants' if they can't meet your essential requirements. Here are some other points to keep in mind:

- Don't hire anyone on the basis of telephone conversation alone.

LIVE-IN AIDE NEEDED

Community college area
only 1 block to bus stop

Modern, 2 bedroom, 2 bath, big kitchen.
Share in return for live-in help to working
college-age man with wheelchair mobility
(2-4 hours per day, on call at night)

Mature individual preferred.
No experience necessary

Call George,
555-5555
5:30 PM to 9:00 PM for details.

To live with George,
Call 555-5555

To live with George,
Call 555-5555

To live with George,
Call 555-5555

To live with George,
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To live with George,
Call 555-5555

- Find out their feelings about performing personal care. If they can't handle nudity and bodily functions, further consideration would be a waste of time.
- Describe your living and social environments, especially as they affect the assistant's duties.
- Ask what kind of work they have done and whether they have work references. Tell them you will be checking references.
- Ask if they are available to work the hours you need assistance and what flexibility they have for additional hours or filling in on short notice.
- Ask if there are any physical or emotional limitations that would make it difficult or impossible for them to do the job.

If applicants don't have an essential qualification, tell them so and end the conversation. There may also be applicants that you just don't feel good about and are not interested in hiring. **Trust your instincts.** You can tell them that you are considering other people for the position and will call them back if you wish to set up an appointment.

If you and the applicant are both still interested, **set up a mutually convenient time to meet in a safe public environment.**

Sample Telephone Screening Form

Name of applicant: _____ Date of call: _____

1. Are you available to work on [DAYS OF WEEK] _____

at these hours _____ AM _____ PM **Yes No**

If additional hours were needed on other days, would you be able to fill in? **Yes No**

Are there any days and times you are absolutely unavailable?

2. Can you perform the following duties:

Assisting with bathing	Yes	No
------------------------	------------	-----------

Assisting with personal care (dressing, hair and nail care, shaving)	Yes	No
---	------------	-----------

Assisting with eating	Yes	No
-----------------------	------------	-----------

Cooking	Yes	No
---------	------------	-----------

Cleaning house	Yes	No
----------------	------------	-----------

Shopping	Yes	No
----------	------------	-----------

Wheelchair maintenance	Yes	No
------------------------	------------	-----------

3. If you are given training, would you be willing to perform the following duties:

Inserting and changing catheter	Yes	No
---------------------------------	------------	-----------

Assisting with bowel care	Yes	No
---------------------------	------------	-----------

Assisting with transfers	Yes	No
--------------------------	------------	-----------

Assisting with range of motion exercises	Yes	No
--	------------	-----------

Assisting with skin care and inspection	Yes	No
---	------------	-----------

4. Do you have the following documents?

Proof of citizenship or work permit	Yes	No
-------------------------------------	------------	-----------

Proof of address	Yes	No
------------------	------------	-----------

Social Security card	Yes	No
----------------------	------------	-----------

Driver's license	Yes	No
------------------	------------	-----------

5. Have you done this type of work before?	Yes	No
--	------------	-----------

6. Please give three references:

Interviewing the Prospective Personal Assistant

The job interview can be a stressful event for both the applicants and the potential employer. As someone who is looking for a personal assistant, you are the potential employer and it is up to you to control the interview process. You need to get information from the applicants, to give information to the applicants, and to find out whether you will be comfortable sharing a very personal, yet professional, relationship with these people.

There are a number of tools and techniques described below that you can use to make the process as stress-free as possible and allow you to come to a good decision.

BEFORE THE INTERVIEW, WRITE DOWN BASIC QUESTIONS AND THINGS SPECIFIC TO YOUR SITUATION

Employment Application

In order to make the interview and selection process simpler and fair, you should begin each interview by asking the applicants to fill out an employment application. This will ensure that you get the kind of information you need as well as having the applicants certify that they are telling the truth. A sample application follows. It is repeated in the appendix so you will be able to copy it easily.

A standardized approach to employment is valuable for a number of reasons. As an employer, for example, you may be required under federal or state law to keep records, including payroll records, employee performance evaluations, disciplinary reports, etc. The employment application should contain the information you need to establish those records.

Using a formal application also avoids the problem of forgetting to ask some questions and then having different information about different applicants to base your decisions on. It also ensures that your applicants sign a statement that they have responded honestly to the questions. While a signature does not necessarily mean that applicants will all be totally honest, it does mean that if you determine they have lied, you have a choice, such as termination of employment.

Review the completed application. Note any unaccounted for gaps in employment history, missing information such as supervisors' names, immediate availability from applicants who are currently working (if they'll quit their currently employer with no notice, they'll do the same to you), and other warning signs of potential problems.

Conducting the Initial Interview

The right person for the job will be someone you are comfortable with, who understands what the job entails, and is capable of performing the duties. It can be a challenge for you, as a person with a disability, to maintain the role of employer while receiving personal assistance, but it can be done. How you conduct the initial interview lays the groundwork for establishing that relationship.

Applicants begin to tell you about their reliability and promptness by arriving for the interview on time. People with disabilities report a high percentage of "no shows" of people who have agreed to an interview. Ask applicants to call you if they will not be able to keep the appointment. Not showing up and not calling show that the applicant is not reliable and should not be considered for employment.

The interview will help to determine whether or not the applicant fits the qualifications and your personal needs. Before the interview, write down a list of questions that address basic information as well as things specific to your situation and needs. Some of this information is asked for in the employment application; the interview lets you explore the applicant's answers and get more information on these topics.

Sample Application for Employment: Personal Assistant

Application for Employment: Personal Assistant

(Please Print)

Name (last, first, middle initial): _____ Date: _____

Street Address: _____

City _____ State _____ Zip _____ M F

Telephone number () _____ Social Security No: _____

EDUCATION (circle one): Less than High School High school or GED Some college College degree

Currently attending school: (give name) _____

Expected graduation date: _____

If you are under 18 years of age, can you provide required proof of your eligibility to work?Yes No

Are you prevented from lawfully becoming employed in this country because of visa or immigration status?Yes No

Proof of citizenship or immigration status will be required upon employment.

On what date would you be available for work? _____

Can you travel occasionally if the job requires it?Yes No

Have you ever been convicted of a felony?Yes No

If Yes, please explain: _____

Describe any special training or skills: _____

State any additional information you feel may be helpful in considering your application: _____

Are you fully capable of performing in a reasonable manner, the activities involved in the job for which you have applied? A description of the activities involved is attached.Yes No

EMPLOYMENT EXPERIENCE

Please start with your present or last job. You should include any military or volunteer work which may be job related.

(over)

Sample Application for Employment: Personal Assistant – *continued*

EMPLOYER 1.

DATES EMPLOYED: FROM _____ TO _____

WORK PERFORMED _____

Name: _____

Address: _____

Job Title: _____ Supervisor/Phone No. _____

EMPLOYER 2.

DATES EMPLOYED: FROM _____ TO _____

WORK PERFORMED _____

Name: _____

Address: _____

Job Title: _____ Supervisor/Phone No. _____

EMPLOYER 3.

DATES EMPLOYED: FROM _____ TO _____

WORK PERFORMED _____

Name: _____

Address: _____

Job Title: _____ Supervisor/Phone No. _____

EMPLOYER 4.

DATES EMPLOYED: FROM _____ TO _____

WORK PERFORMED _____

Name: _____

Address: _____

Job Title: _____ Supervisor/Phone No. _____

REFERENCES:

1. Name: _____ 3. Name: _____

Phone #: _____ Phone #: _____

Address: _____ Address: _____

2. Name: _____ 4. Name: _____

Phone #: _____ Phone #: _____

Address: _____ Address: _____

I certify that all answers given here are true and complete to the best of my knowledge. I authorize investigation of all statements contained in this application for employment as may be necessary in arriving at an employment decision.

Signature of Applicant

Date

Areas you may want to cover with interview questions include the following:

- Background information: name, date of birth, address, and social security number.
- Education: level, including type of degree (RN, LPN, or nursing assistant), if any; educational goals; special training.
- Experience: any experience related to being a personal assistant or other health-related experience (e.g., volunteer in nursing home, caregiver to a family member). Has the applicant been around a person with a disability? What kind of work have they done and liked the best?
- Duties: Is the applicant able and willing to perform the duties necessary for your specific situation, those that you listed on your needs assessment (for example, bathing, dressing, grooming, meal preparation, transfer assistance, driving, and bowel/bladder care)? Will they feel comfortable driving a large vehicle like a van? Do they understand that physical lifting may be involved?
- Schedule: specific scheduling needs (yours and theirs) and the hours that they can work, what breaks they need, and their expectations for holidays and time off. If they'll be living with you, would they mind getting up in the night to turn you or help you go to the bathroom?
- Attitudes: How do they feel about disability? How do they deal with boredom and stress? Can they make decisions?
- Salary: Discuss the rate of pay and the payment schedule (every week, every other week), and tax deductions.
- Benefits: Talk about any non-cash benefits of the job. These may be easy to identify if the personal assistant will be living with you (room and board, etc.) but don't overlook others that may be part of the job, depending on your specific situation, such as training in the skills needed to be a personal assistant, free meals, English language instruction, computer access, opportunity to travel.
- Personal preferences: ask if the applicants smoke, drink, listen to opera or country music, etc., especially if they will be living with you.

- Travel: Are they available to travel with you if necessary?

In addition to these types of information, you should talk about any other issues that are important to you. Add other questions related to your situation.

For instance, the roles of other people in your home and any relationship the personal assistant will have with them should be discussed. Which of your friends and family members live with you or have "house privileges"?

Are your assistants' family and friends welcome, especially live-in assistants?

To understand the importance of the position, the applicant must also understand your functional limits and the reason assistance is required. You can use the job description you developed earlier to explain

what will be required. It is important to be frank and honest during this initial meeting so that the applicant understands the personal dynamics and the potential physical contact between the two individuals.

Do not try to make the job sound easier or less time-consuming than it actually is to persuade an applicant to take the job. They may take the job, but they won't stay long.

Find out how long the person will be able to stay in the job. While normally the longer a person is available the better, you may want to hire a qualified person who is only available for a short time. This is particularly true if you are waiting to be discharged from the hospital, if you are starting school or a job, if your previous assistant has left unexpectedly, or if you are otherwise in transition. You will have someone to provide care while you look for a long-term replacement.

There are some important traits to look for in a personal assistant. The individual you hire should be:

- organized
- stable
- reliable
- professional
- patient
- compassionate
- experienced in the services he or she will be providing
- flexible
- respectful of your privacy

DO NOT TRY TO MAKE THE JOB SOUND EASIER THAN IT IS

When you ask an applicant questions, take notes of the answers. Pay attention to the following:

- Does the applicant appear comfortable around you?
- Does the applicant have an attitude that makes you uncomfortable?
- Can you and the applicant understand each other—does an accent or hearing problem impede communication?
- Do you like the applicant on a personal level?
- Will the applicant be able to deal with nudity and bodily functions in an acceptable manner while helping you bathe, dress, or do bowel and bladder care?
- Is the applicant's energy level appropriate to the time of day and assistance provided?

Remember, this person may be providing some very personal services for you or sharing your home. You need to hire somebody with the attitude and personality that make you feel comfortable and secure.

Allow applicants to ask you questions about your disability and lifestyle. They need to know these things to be able to do the job well. Applicants who only seem interested in the salary and benefits may not appreciate the nature of the job and the skills required.

When you complete the interview, tell applicants that you will be checking references and will call them back with your decision. It is **never** a good idea to hire someone on the spot. Be sure you do call back all of the people you have interviewed; as you may know from experience, it is unpleasant for job applicants to be left hanging.

Applicant Files

After the interview, begin a file for each person you choose to interview. The file should include the application, a resume if the applicant sends it to you, the results of your reference checks, a copy of the contract, and any other documents you will accumulate during the employment process.

It is important to have a file card for each personal assistant, even those who may have been employed for only weeks or days. Include the name, address, phone number, an emergency contact person and telephone number, date of birth, social security number, driver's

license number, date hired, and final date of employment. The name on the file card should be recorded exactly as it appears on the social security card.

You will be adding documents to each employee's file as time goes by, such as time sheets, payment records, and performance evaluations. This is also a place to keep confidential notes to yourself about any issues that may arise with the employee.

Checking References

On the employment application, you asked for references from the applicant. Explain to the applicant that you are checking references on all the applicants because they will be working in your home providing very personal care.

Ideal references would be people for whom the applicant has performed the type of work you will need done. Other acceptable references are other employers, job counselors, teachers, and ministers or other religious leaders. References should be checked for any applicant you are considering hiring, even if it means writing or calling out of state. The time and effort you expend on this will be well worth it if the references help you avoid hiring problem assistants. References need to be checked and this information kept in the applicant's file.

It may be easier to check the references of a person who has held jobs in your area. It is a positive sign if the applicant has held a position for a long period of time as opposed to having jumped from job to job, unless there is a good explanation for the job changes.

Below are some questions for you to consider asking.

When you call the applicant's references, explain why you are calling and the type of work the applicant would be doing for you. Ask for their honest opinion and promise to treat the information as confidential and to not voluntarily disclose the information or its source to others.

All references should be asked the following questions:

- What was your relationship with the applicant?
- How long have you known the applicant?
- What are the applicant's strengths and limitations?
- How does the applicant react to stress?
- Do you consider the applicant an honest person?

**IT IS NEVER A
GOOD IDEA TO
HIRE SOMEONE
ON THE SPOT**

- Do you consider the applicant reliable?
- How well does the applicant get along with others?
- Do you think the applicant would be good at this type of work?

If the reference is provided by a previous employer, try to ask the questions listed below. Be aware that some employers will only verify dates of employment and not make recommendations for privacy reasons and for fear of liability suits.

- How long was the person employed?
- Was the applicant dependable?
- Is the applicant able to work independently?
- How often was the person absent without notice?
- Did the person deal with money on the job?
- How well does the applicant take supervision and criticism?
- Can the applicant perform diverse tasks?
- Why did the applicant leave the job?
- Would you rehire the applicant? If not, why?

A Sample Reference Check Wrk Sheet follows. Another copy is in the appendix.

You may also want to consider having a driving record and criminal background check performed before you hire an individual. If something doesn't sound right, if a reference tells you something different than the applicant did, or if you are relatively isolated or feel particularly vulnerable, a background check may be a worthwhile investment. Check with your local police or department of motor vehicles to see if they perform this service or can refer you to agencies that do.

Making the Selection

Having interviewed the applicants and checked references, you must now consider the information you have gathered. Compare how well each applicant meets the items you specified on the Sample Needs Assessment Work Sheet, Sample Consumer Preferences Work Sheet, and, if applicable, Sample Live-in Assistant Preferences Work Sheet. While you are highly unlikely to find any one person who fits all your preferences, you are looking

for someone with all of the qualifications you decided were “absolutely essential,” as well as most of the “very important” ones and as many of those that “would be nice” as possible.

Some of these issues are basic. Don't hire someone whose references told you about chronic attendance problems. If you need your assistant to drive, make sure applicants have a valid driver's license and a good driving record. This is important for both your safety and your insurance.

Pay particular attention to the answers you received from applicants' references to the questions on honesty, reliability, getting along with others, why applicants left their previous jobs, and whether they would be rehired.

When selecting assistants, select people based on whether you think they can be trusted. You are trying to select an employee who will provide dependable care on a regular basis.

How is the applicant's physical and emotional health? Emotional problems can be difficult to deal with and physical problems may reduce an assistant's reliability.

Someone who does not fit the bill for being your primary assistant may be suitable as a back-up. If someone has most of the qualifications you want but is missing something essential, you may be able to find someone else to fulfill just that need. Be prepared to be flexible.

Are your lifestyles compatible? Do not think you have the right to control the life of someone you hire. What your assistants do in their off-duty hours only concerns you if it affects the quality of your care. For example, differing tastes in music between you and live-in assistants may be resolved through the use of earphones when the assistants are at home but off duty. However, if your assistants are “on-call” while at home, you must be able to get their attention despite the earphones.

Remember, you are not hiring a friend or lover, a sister or mother. You are hiring someone to perform specific duties involved with your personal-care needs, not to meet all of your social and emotional needs.

At the same time, trust your gut reactions. If being around a person makes you irritable, confused, angry, uncomfortable, even if you can't pinpoint the reason, **do not hire that person.**

SELECT ASSISTANTS YOU THINK CAN BE TRUSTED

If you feel comfortable with a person, think they would meet your needs, are satisfied with the information that the references have given you, and think you would like to offer the position to the applicant, set up a time to meet with the applicant in your home. This meeting is important especially if the person will be living with you. It is not unreasonable for a person to want to see the working and living environment before accepting a job.

It may be a good idea to get a second opinion before you hire someone, especially if you are undecided about a person. At the second meeting you may want to have a family member, friend, or member of your healthcare team with you. They can help you clarify how well the applicant meets your needs and how well your personalities fit.

When you have identified a qualified applicant, offer a two-week trial period to see how it works out.

Sample Reference Check Work Sheet

Name: _____ Date: _____

Reference: _____ Tel. #: _____

How long known? _____

Relationship? _____

Reliability? _____

Promptness? _____

Honesty? _____

Driving record? _____

Ability to get along with others? _____

Strengths: _____

Limitations: _____

Good at this type of work? _____

Able to handle stress? _____

For employers:

Start date? _____

Termination date? _____

Reason for termination? _____

Salary? _____

Attendance record? _____

Dependable? _____

Work independently? _____

Reaction to supervision? _____

Reaction to criticism? _____

Duties? _____

Rehire? _____

Recommended? _____

After a week or less, you should know if the applicant will work in the job. Ideally, your current assistant or a member of your health-care team can work with and train the new assistant during this period.

Let all applicants know your decision within a week of your final discussions with them, whether it's after the phone call, the initial interview, or the meeting in your home. You will probably call people you want to hire; don't forget to send letters to candidates you do not select. You can send out one of two form letters: one for people you want to keep in your files in case you need them in the future and one for people you absolutely will never hire. Sample letters follow.

Do not hire someone out of desperation. You may think having an unsuitable person is better than having no one, but that may not be the case. If you use all the resources available, you will increase your chances for success in finding suitable personal assistants.

Have a Backup Plan

It is wise to have more than one personal assistant. Especially if you need care seven days a week, no one person will always be available. Personal assistants must have some days off and you need to find someone else to care for you then. A personal assistant could become ill and you could be left without anyone to care for you. Or, if a personal assistant decides to quit without notice, you would be left without anyone to care for you if you don't make alternate plans.

If you have more than one personal assistant and one is unexpectedly unable to keep to the schedule, you can ask the other(s) to work overtime. (You must be prepared to take "no" for an answer and to pay for any overtime worked.)

Still, at some time or other, you will more than likely find yourself without a personal assistant when you need one. You need to have a backup plan.

Do a second needs assessment as an alternative plan. What can you cut down on, for a short time? Can you let some housecleaning go? Can you simplify your meals? Be realistic about what you can eliminate without sacrificing your health and safety.

Be aware that sacrificing personal hygiene can put you at risk for secondary health conditions. Failure to do weight shifts and pressure relief can lead to skin break-

down and pressure ulcers. Prolonged contact with moisture can also lead to skin breakdown and infections of the urinary tract and genitals.

Think of alternative means of getting your essential needs met. You have to eat, of course. Can you eat with family or friends? Does your community have a Meals on Wheels program that you might qualify for? Since this, as well as other possible alternatives, requires advance application, assessment, and scheduling, you need to make arrangements before you are left without assistance.

You may find several potential assistants when you conduct your original interviews. You may interview a person who is not available for the hours you need on a full-time basis, but could work when the primary assistant has the day off or who could act as a substitute.

Some communities have organizations that can supply assistants as part of a back-up plan, such as a visiting nurse service, center for independent living, or organization for people with disabilities. Religious establishments can also be a resource. Or you may make an agreement with another person who has an assistant to share assistant services on a temporary basis.

Arrange with a family member or friend to know your personal care so you can call on them as a last resort. You may be able to arrange with a neighbor who wants to earn a little extra money occasionally to know your care and be available when you have a need. If you haven't overused them in the past, they may come through for you when you have no personal assistant.

Since we all forget how to do things if we don't do them in a while, try to use your backup helpers occasionally when it isn't a crisis. They'll become more comfortable with providing your care and it won't feel like so much of an emergency when you're without a personal assistant.

Realize that the same individual doesn't have to supply all of your needs. A visiting nurse will assist with bowel and bladder care, for instance, but will not perform housecleaning or run errands. You (or your family, friends, and neighbors) may know a responsible teenager who would like to earn some money performing those non-skilled tasks.

The most important part of handling the sudden loss of your personal assistant is planning for the situation and having contingency plans. You should explore all your options and be aware of your resources.

Sample Form Letter to Rejected Applicant with Potential

September 30, 1999

P.A. Doe
Any Street
Any Town, ST 12345

Dear Applicant:

Thank you for your interest in the job as personal assistant. I am pleased that you contacted me regarding possible employment and gave me the opportunity to review your qualifications.

Unfortunately, at this time your skills and schedule of availability do not match my needs and I am unable to offer you employment.

However, I would like to keep your name and number on file, so I can call you in case your schedule or my needs change in the future.

Thank you again for your interest.

Sincerely,

I. M. Theboss

Sample Form Letter to Rejected Applicants

September 30, 1999

P.A. Doe
Any Street
Any Town, ST 12345

Dear Applicant:

Thank you for your interest in the job as personal assistant. I am pleased that you contacted me regarding possible employment and gave me the opportunity to review your qualifications.

Unfortunately, at this time your skills and schedule of availability do not match my needs and I am unable to offer you employment.

Thank you again for your interest.

Sincerely,

I. M. Theboss

Being A Good Manager

Personal assistants play an important part in the lives of the individuals with whom they work by allowing them to maintain their independence. At the same time, it is an unusual relationship because, unlike in the usual employer/employee relationship, the boss is dependent on the employee. This relationship is one that requires tact and diplomacy by the employer. When this relationship is developed and a proper balance maintained, the relationship is beneficial to both.

When you decide to hire a personal assistant, you agree to provide certain salary and benefits in return for specified services to be performed at certain times. It is important that your agreement be spelled out, on paper, and that the performance is documented throughout the time you employ the personal assistant.

There are several reasons why this is important. First, the person you hire must know what it is that you need to have done. If this is clearly defined up front, the person will know what is expected and be better prepared to do it.

SHOW YOUR APPRECIATION

If disputes arise at any time about duties or schedules or other issues, it is easier to settle them if the expectations are written down. We all sometimes forget or misunderstand what is said; for example, was I supposed to do that once a day or once a week? If it's written down, you don't have to rely on memory.

Because of the intimate nature of the services you may need, it can be a challenge to maintain an appropriate professional relationship. Use of a written job description and personal assistant time sheets helps to establish and maintain this relationship. They help make sure that each of you is fulfilling your part of the relationship.

If a problem does arise, such as absenteeism, it will be helpful to you to have a job description with the hours specified and employee time sheets showing the actual hours worked. These documents are evidence that can assist you in correcting the problem. For instance, identifying a particular day when the assistant is habitually late can indicate a scheduling conflict that needs to be resolved. In the worst case, if you need to terminate the relationship with the assistant, you have evidence of what the problems were.

The Mechanics of Management

- Maintain a sign-in log for your assistants so there will be no misunderstanding regarding the hours and days worked.
- Track changes in schedules, including the dates and times where one personal assistant had to fill in for another, or when vacation and sick days are taken by each personal assistant.
- When your personal assistants leave for the day, confirm with them when they will work with you next by saying something like, "See you tomorrow morning at 8:00."
- Make sure your personal assistants are able to leave work on time. Although sometimes this may be difficult for you, being able to leave work when expected is important to an employee. You need to respect the fact that they have a life outside of helping you.
- Notify your personal assistants of any events in your life that may affect them (doctor appointments, visitors in the house, changes in old routines, or new equipment added to your routine).
- Make sure you pay your personal assistants on time with the right amount, so that they do not have to ask you for their pay. The amount and schedule of payment should be specified in the letter of employment.
- Keep an ongoing list of chores to be done, errands to be done, and information you need to give to employees.
- Monitor your supply of medications and other supplies.
- Keep good records of all of the personal assistants who have worked for you.

Work Schedules

Hours of work are an important aspect of your arrangement with a personal assistant. Listed below are some considerations in making decisions regarding establishing a schedule for employees that will benefit both you and the personal assistants who provide services for you.

- Try to distribute the tasks evenly so that the assistant does not have some exhausting days and other days with too little to do.
- Be reasonable in your expectations. It is not a good idea to hire one person to do all your care. The assistant needs some time off and you both need time away from each other. If you need help seven days a

week, you will need several different people—for mornings, evenings, and weekends. When several assistants are scheduled, be sure to post the schedule so there is no confusion.

- A written agreement should be signed by both you and the assistants who provide service for you that clearly states the work schedule on which you both agree.
- Financial arrangements for any additional hours or changes in schedules or holidays worked should be included in all written agreements.
- Include any special arrangements for days off, sick days, holidays, and vacations in written agreements.

Letter of Employment and Financial Arrangements

To avoid any misunderstandings, it is helpful to have a written letter of employment from you to your personal assistants. The letter should cover such matters as hours of work, salary, vacation and sick leave, and the time needed for notice when the person decides to leave the job. There should also be a clear description of the arrangement made regarding taxes, Social Security, and any noncash reimbursement.

Both you and the employee should have a copy of this letter. Keep your copy in your employment files. Specifics regarding tax and Social Security information are covered in another chapter of this manual, but this information will also need to be discussed with the assistant and may be included in the letter or in a separate written agreement.

A sample letter follows. You would need to write one that suits your particular needs. Also included is a copy of a time card that can be used to keep an accurate record of the dates and times that the personal assistant worked. Completed time cards should be kept in your file. Both of these documents are repeated in the appendix for copying or revision.

Employee Files

The personnel files should include each employee's employment application, resume, references, and, of course, addresses, telephone numbers, and Social Security numbers. Keep your letter of employment and employee time sheets. Included in this file should also be performance evaluations and the reason why the personal assistant left or was terminated. Keep these records for at least 7 years. Be sure to include the payroll and tax records.

Some of the information in employee files is confidential. You should take steps to restrict access to the files:

- Password protect all computer files.
- Keep the files in a locked cabinet or drawer.
- Enter information in the files when you are alone.

Privacy and Confidentiality

Before you hire a person, you need to discuss issues of confidentiality and privacy. Specify what things you want to keep confidential, such as medical records, financial information, family secrets.

Especially if you have live-in personal assistants, you need to respect each other's needs for privacy, when using the telephone, having company, and handling financial and personal information. Respect each other's bedrooms and personal property. Food can be an area of conflict; you must communicate what is shared, what is yours alone (especially if you have special dietary needs), what is being saved for a special occasion.

If you discuss personal problems with your personal assistants, remember that you have not hired them to be counselors. They may not have the training or experience to give you the best advice or feedback. Some people are uncomfortable listening to others' problems and being asked for advice. Don't force the role of confidant on your assistant. If your assistants are willing to listen to you, be prepared to reciprocate and to listen when they need someone to talk to.

The Art of Management

Emphasize open communication. Being open to suggestions and comments is one way of showing respectful behavior towards the people providing services for you. Show your appreciation.

Being a supervisor may be a new role for you. It does not mean being a dictator, but guiding your assistant to provide you with the care you need. Because of the close contact between you and your personal assistant, it is important for you to use supervisory skills to stay in control, to solve problems, and to maintain a good relationship with your assistant.

Use the same tact and warmth with your personal assistant as you would with a friend. Expect that even an experienced assistant will forget items of your daily routine at times. Try to be tactful with your reminders. If you find you are repeatedly short-tempered with your assistant, try to objectively retrace the events and view them as a third person would. Try to see if there is

Sample Letter of Employment

September 30, 1999

P.A. Doe
Any Street
Any Town, ST 12345

Dear P.A. Doe:

This letter offers you a job as live-in personal assistant to me, I.M. Theboss, under the following conditions of employment, hours of work, compensation, and general responsibilities. Refer to the attached job description for details of duties.

The work schedule will be Monday through Friday, from 6:30 to 8:30 a.m. and from 5:30 to 7:30 p.m. As needed, you will accompany me on an outing (theater, movie, concert, etc.) approximately one evening per week, to be negotiated on an individual event basis. I will pay all expenses for such outings, as well as for your time.

Compensation will be at the rate of [\$?.??] per hour paid weekly on Friday afternoons. You need to complete and give to me an IRS form W-4, with your withholding information. I will withhold federal and state income taxes and FICA (Social Security) taxes weekly. I will give you a form W-2 for your use in filing your income tax statement annually.

In addition, you will have the use of the second bedroom in my apartment, plus access to the laundry room and the storage bin in the basement. The only utility bills you will be responsible for are long-distance phone calls and, if you wish to have a television in your room, the cable hookup and monthly bill. I will pay all other utility bills. My van is equipped with hand controls and other special equipment and is not available for your use.

Except for emergencies, both you and I must give at least two days advance notice in the event of a planned absence. In an emergency, notification must be given as soon as possible.

Theft or unauthorized use of my property, any use of controlled substances, use or being under the influence of alcohol during working hours, or endangerment of my health or safety, will result in termination. We each agree to give two weeks notice of termination for other causes.

My apartment building is a no-smoking environment. It is a condition of my lease that I do not smoke or permit smoking by anyone else in my apartment or any portion of the premises. Since violation of this policy could endanger my lease, this is not a matter for negotiation.

We will cooperate so that tasks required can be completed in a reasonable amount of time. We will respect each other's dignity and privacy. I look forward to a mutually rewarding relationship.

Sincerely,

I. M. Theboss

Sample Personal Assistant Time Card

Time Card

Employee's Deadline: Must be turned in to employer by the first day of the new month.

Employee Name: _____ Month: _____ Year: _____

Day																
Date	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	
Start Time																
End Time																
Start Time																
End Time																
Hours Worked																
Holiday																
Sick Leave																
Annual Leave																

TOTAL:

Day																
Date	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Start Time																
End Time																
Start Time																
End Time																
Hours Worked																
Holiday																
Sick Leave																
Annual Leave																

TOTAL:

I certify that the number of hours shown above is a true and accurate account of the time worked for the month.

Employee Signature

Date

actual fault here and what proportions of blame fall to which person. Before you confront, snap at, or argue with your assistant, ask yourself, “Is this a real problem that hampers my needs or is it just a personal habit that gets on my nerves?” Also ask, “Is this an annoying personal habit of mine?” If you decide it is an issue that needs to be talked about, discuss it when you are both in a receptive, unhurried frame of mind. Make sure both people’s points of views are acknowledged. You will find that thinking before you speak helps you to maintain control.

Your assistants have formally agreed to be responsible for your needs for a certain number of hours, as specified in the employment contract. You do not have an open charge account on your assistants’ time. If you need help on a special occasion or project, discuss it with your personal assistant in advance. If it is time to change the bald tires on your wheelchair, for example, or you want to go see a movie and need your assistant to accompany you, try to schedule it for a mutually agreeable time. Don’t forget to add payment for these additional hours to your assistant’s regular wages.

Make it clear to your personal assistants that you value their role—they are helping professionals, not babysitters. They need to be your eyes to see if your needs are being taken care of, ears to listen carefully, and legs to assist you in everyday and emergency situations.

Your relationship should be founded on mutual respect. Your assistant is helping you to maintain your independence and dignity and must treat you with respect. In return, you must pay them the same respect. “Please” and “thank you” are magic words in every relationship.

Performance Appraisals

To be a good manager, you should provide your personal assistants with periodic written evaluations of their work productivity and behavior. A formal report, often called an annual evaluation or performance appraisal, serves several purposes: (1) determine job competence, (2) motivate the person to higher achievement, (3) recognize accomplishments, (4) improve communication between the employee and the manager, (5) identify the employee’s training needs, and (6) document unsatisfactory performance.

Evaluating an employee’s performance objectively is difficult, since it involves human judgment that is subject to the influences of prejudice, bias, and other extraneous

factors. You must keep this in mind when selecting a tool to use for the performance appraisal.

There are many forms you can use for a performance appraisal, including checklists, rating scales, and anecdotal notes. The type of report that you choose is a personal decision. What is important is that you share the areas in which your personal assistants will be evaluated during your initial interviews so that they will not be surprised when they receive their performance appraisal. This also lets them know what your expectations are for their satisfactory employment.

It is recommended that you provide a written performance appraisal within the first 90 days of employment and then once or twice annually. Each appraisal allows for discussion in which any personal strengths can be reinforced, training needs can be identified, and any performance deficiencies can be addressed.

One form of evaluation uses a scale to rate employee’s performance of key traits of the job. It also provides space for written comments and anecdotal notes. A sample of such a performance evaluation form is included here and in the appendix. A sample completed form is also given. You can modify this form to match your particular needs.

Once you have completed an evaluation you should schedule a quiet, private time in which you can present it to your personal assistant. Give the employee a chance to read it, ask for more details, and respond. You should be prepared to expand on the comments you have made in the written report. It is especially helpful if you can talk about what the employee is doing well, to reinforce exceptional performance. If there are performance problems, you should set a time limit for your assistant to correct any performance deficiencies.

After you have finished your discussion you should both sign two copies of the report. Keep one in the employee file and give one to the employee. Before the meeting ends, you should tell your personal assistant the schedule for the next evaluation.

Ending a Relationship with a Personal Assistant

In all but the rarest of cases, you and your personal assistants will sooner or later come to a parting of the ways. There are “no fault” reasons why you or your personal assistants need to end your relationship:

Sample Performance Evaluation: Personal Assistant

Application for Employment: Personal Assistant

Name: _____ Date: _____

Period of Evaluation: _____

RATING SCALE:

- 5 -Far Exceeds** (Performance is exceptional. Initiative and commitment are never in question, even under the most challenging circumstances)
- 4 -Consistently Exceeds** (Performance consistently exceeds job requirements. Meets challenging work goals and independently takes on tasks)
- 3 -Fully Meets** (Performance meets and occasionally exceeds job requirements. Individual skills, initiative, and judgment are being used appropriately)
- 2 -Minimally Meets** (Performance is barely satisfactory. Sometimes requires repeated instruction)
- 1 -Unsatisfactory** (Overall performance is below minimum standards due to inability, lack of interest, or other factors. Immediate improvement is needed or employment may be terminated)

EVALUATION FACTORS:

Job Knowledge – *Knows techniques, methods, and other information applicable to the duties of this job.* Rating: _____

Attendance/Punctuality – *Adheres to job schedule.* Rating: _____

Quantity/Quality of Work – *Is thorough, accurate, and complete in performing tasks.* Rating: _____

Communication – *Understands written and verbal instructions.* Rating: _____

Cooperation and Interpersonal Skills – *Works well with others; accepts assignments and supervision.* Rating: _____

Initiative and Creativity – *Starts and completes tasks independently, suggests new ideas.* Rating: _____

Overall Performance Rating: _____

TRAINING PLAN: List any training needs for the upcoming evaluation period.

EMPLOYER SIGNATURE: _____ **DATE:** _____

I have read this evaluation and discussed it with my employer.

EMPLOYEE SIGNATURE: _____ **DATE:** _____

EMPLOYEE COMMENTS:

Sample Completed Performance Evaluation: Personal Assistant

Application for Employment: Personal Assistant

Name: P.A. Doe Date: July 20, 2001

Period of Evaluation: January — June, 2001

RATING SCALE:

- 5 -Far Exceeds (Performance is exceptional. Initiative and commitment are never in question, even under the most challenging circumstances)
- 4 -Consistently Exceeds (Performance consistently exceeds job requirements. Meets challenging work goals and independently takes on tasks)
- 3 -Fully Meets (Performance meets and occasionally exceeds job requirements. Individual skills, initiative, and judgment are being used appropriately)
- 2 -Minimally Meets (Performance is barely satisfactory. Sometimes requires repeated instruction)
- 1 -Unsatisfactory (Overall performance is below minimum standards due to inability, lack of interest, or other factors. Immediate improvement is needed or employment may be terminated)

EVALUATION FACTORS:

Job Knowledge – Knows techniques, methods, and other information applicable to the duties of this job. Rating: 4
P.A. knows our routine well; also took CPR class to increase skills.

Attendance/Punctuality – Adheres to job schedule. Rating: 3
Overall good; June—the last week of school—there were some latenesses without notice. apparently a problem with child care has been resolved

Quantity/Quality of Work – Is thorough, accurate, and complete in performing tasks. Rating: 3
P.A. is very good at our daily routine, but has gotten rattled by surprises.

Communication – Understands written and verbal instructions. Rating: 4
P.A. takes direction well; grasps new tasks with minimal instruction

Cooperation and Interpersonal Skills – Works well with others; accepts assignments and supervision. Rating: 3
Gets along well with most people (including me!); there seems to be some friction with relief aide—different working styles?

Initiative and Creativity – Starts and completes tasks independently, suggests new ideas. Rating: 4
Following my attack of autonomic dysreflexia, which upset us both, P.A. showed great initiative—went to the library, got online, and found the consumer guide AD: What You Should Know that we've both found helpful. We're better prepared to prevent another episode and know what to do if it occurs.

Overall Performance Rating: 4
P.A. has become a very reliable, competent aide, helping me through my daily routines with calmness and efficiency. Has taken initiative to get more training and learn more about my condition and how to handle problems that may arise. I hope we have a continuing relationship into the foreseeable future.

TRAINING PLAN: List any training needs for the upcoming evaluation period.

Will look into course on bowel management.

EMPLOYER SIGNATURE: I. M. Theboss DATE: July 20, 2001

I have read this evaluation and discussed it with my employer.

EMPLOYEE SIGNATURE: P.A. Doe DATE: July 20, 2001

EMPLOYEE COMMENTS:

If the relief aide would clean up after herself and not leave me to clean up items she's used, it would eliminate the friction.

- Your physical condition and thus your needs, change.
- Your schedule changes and is now incompatible with theirs, and vice versa.
- Your living arrangements change.

If personal assistants leave you on good terms, it may be worth asking if you may call on them in an emergency. If they agree, determine the times they would be available and keep a record of their telephone numbers. You never know when an illness or other emergency may occur and an alternate personal assistant is needed.

Your assistants may also quit for causes related to the work. Much of the information in this manual will help you be a good manager and avoid the reasons many assistants quit:

- Incomplete, inaccurate job description.
- Disorganized duties or working environment.
- Bad communication with the boss.
- Unreasonable expectations on the part of the boss.
- Lack of respect or appreciation.
- Low pay, irregular pay, requests for uncompensated services.

If an assistant quits or you have an amicable parting of the ways, you have a few managerial duties:

- Give as much notice as possible and try to arrange overlap into your new situation or assistants.
- Offer to serve as a reference or to write a letter of referral.
- Make sure final payment is made on any salary due.
- Get back any keys your assistant had.
- Keep a permanent address or phone number for sending tax information at year's end (if applicable; see the chapter called Tax Responsibilities).
- Send a W-2 in January to everyone who worked directly for you (if applicable; see the chapter called Tax Responsibilities).

Firing an Employee

Unfortunately, you may need to fire an assistant, for any of the following reasons:

- Dissatisfaction with the work that cannot be resolved.
- Neglect or abuse.
- Theft of money or property, including misuse.
- Illegal or inappropriate drug or alcohol use.

In these cases, the primary concern is ensuring your immediate and continuing safety.

- Consider carefully whether to give any notice before the firing. In most cases, particularly those that involve offenses given in your letter of employment as reasons for immediate termination, safety dictates giving no notice. Any notice gives opportunity for further offenses. Even if you feel safe being cared for by someone to whom you've given notice of firing, many employees will not return to work after being fired.
- Rehearse what you will say with a friend.
- Try to make arrangements for a replacement before the firing, so you are not left without a personal assistant.
- Choose a time when you are calm and as independent as possible.
- State the grounds as simply and objectively as possible and make it clear your decision is immediate and irrevocable.
- Have someone with you as a witness and for moral support and protection if you anticipate a violent response.
- Get back any keys your assistant had.
- Have the locks changed immediately.
- Find out where to send any final paycheck due.
- Keep a permanent address or phone number for sending tax information at year's end (if applicable; see the chapter called Tax Responsibilities).
- Send a W-2 in January (if applicable; see the chapter called Tax Responsibilities).

Insist that a live-in assistant move out immediately. Remain present while they move out so they don't damage or steal your property. You can arrange to have a police officer present as well to assist in their removal, if you call the police nonemergency number in advance.

No one likes to fire an employee and the personal nature of the services your assistants provide you makes it that much more difficult. For health and safety reasons, you should not remain in a bad situation with your assistants. These steps should help you get out of such a situation.

As with so many areas of life, prevention is better than cure. This manual's recommendations for carefully interviewing, screening, and selecting your assistants are designed to prevent situations where you have to fire an employee or risk endangering yourself and your health.

Training Personal Assistants

After you have hired your personal assistants, it is important to train the individuals for the job they will be doing for you. You should find out what training, if any, they have had and then plan what additional training they will need. Even if someone has been trained to perform a task, you may have developed your own methods and preferences about how it should be done that you will have to communicate to your assistants.

As an employer of a personal assistant you must now take on a role of being a supervisor. Supervising does not mean that you control what the personal assistants do, but that you show them what to do for you. It is important to guide your assistants in a direction that is the most efficient in meeting the needs that you outlined in your needs assessment. Training personal assistants is accomplished by both of you working together in a professional and friendly manner.

Personal Care Checklists

At the beginning of employment, develop checklists of the tasks that need to be performed, based on your needs assessment. This will help avoid conflicts about duties your assistant is to perform and help ensure that you get the care you need.

Here are some general guidelines for developing your individualized checklists:

- Be brief—Make the steps as short as possible.
- Put steps in correct order—Arrange the steps in the order in which they should be performed. Make sure to specify steps that are essential or often neglected.
- Include what, when, where—State what materials are needed and when and where the task will be performed.
- Avoid how—Much of the how to should be taught while the task is being performed.

It is best to arrange the checklists in chronological order; for example, you would put first the morning routine of bowel and bladder care, bathing, and dressing. You could also arrange the checklists by daily (e.g., dressing, eating), weekly (e.g., shopping), and monthly (e.g., wheelchair maintenance) tasks. Having the checklists arranged in an organized fashion simplifies things for both you and

your assistants. The checklists become a very clear and complete job description. As time goes by, these duties become routine and a checklist may not be needed.

An example of a personalized care checklist follows. There is another copy in the appendix.

AS AN EMPLOYER OF A PERSONAL ASSISTANT YOU MUST NOW BE A SUPERVISOR

Training Tips

In some cases, the personal assistants may require specialized training before being hired, such as in CPR, first aid, bowel and bladder routine, skin care. It is important to be sure, before you hire personal assistants, that they have or get this training.

Your personal assistants may need to learn about the nature of your disability and be prepared for crisis that may result, such as autonomic dysreflexia from a spinal cord injury or a syncopic episode from a stroke. If your disability includes cognitive impairment, your assistants need to be alerted to that and to measures you use to overcome it. For example, if you have memory lapses from multiple sclerosis, your assistants must know they need to enter such things as schedule changes on a master calendar and not rely on your remembering a verbal message.

One of the first steps is to familiarize your personal assistants with the areas of your house that they will be using (bedroom, bathroom, kitchen, and other areas as they apply to your situation) and where you keep your supplies. Make sure they know how to use appliances and your medical equipment.

It is also important to tell your personal assistants about the medications you are currently taking and the side effects that any of them may have. If you have a reaction, your assistants must know how to handle the situation.

Sample Personal Care Checklist for Morning Routine

Personal Care Checklist

Getting Ready

1. Get clothes ready
2. Prepare bath water
3. Check bathroom temperature
4. Make sure needed materials are available

Routine

1. Assist with bladder catheterization
2. Assist with bowel by inserting suppository and digital stimulation
3. Assist in clothing removal
4. Move from bed to bath
5. Wash and rinse body
6. Assist with hair care
7. Move from bath to dressing area
8. Dry body thoroughly
9. Conduct skin check for pressure sores
10. Apply lotion or powder
11. Apply deodorant
12. Shave
13. Assist in dressing
14. Move to wheelchair
15. Assist with tooth brushing
16. Move to breakfast area

Clean Up

1. Put away all materials
2. Clean and disinfect bladder and bowel care materials
3. Clean bathroom

Also discuss with the assistants how much mobility you have. This will make it easier to perform tasks such as lifting, moving, or transferring.

Clearly and respectfully explain what you require, rather than making the assistant try to figure out the type of care you need. Go through the checklists step by step for each task or routine. If possible, demonstrate exactly what the assistant is to do and the way you prefer or need to have it done over. **An initial training period during which a new assistant can observe and learn from your current assistant is invaluable.**

Give them a chance to see what needs to be done, ask questions, and then do it themselves with someone who is experienced present. Don't try to train your assistants in everything they need to know in one session.

Encourage your personal assistants to ask questions while you are explaining job duties. If there is a particular way that you want a task completed, do not hesitate to say so. However, be flexible and listen to the personal assistant, who may have good suggestions for ways to accomplish some duties.

The following are some general tips that should make it easier for you to train your personal assistants.

- Have an ample supply of medical, personal hygiene, and cleaning products. Either you or your personal assistant should keep an inventory of these products.
- Color coding or marking items may be useful to new personal assistants or for those who rarely perform a particular task. You may then refer to a color or a number when explaining how to do a particular task.

- Have your home organized, so that you know where things are located. Encourage your personal assistants to keep it this way. You need to know where items are to assist those who help you.
- Develop a standard routine to get tasks done with the least amount of time and with the least disruption.
- Have realistic expectations. People don't always get something right the first time. They make mistakes, but practice makes perfect.

Additional training resources may be available from your primary health-care provider or your rehab center. Other sources include Centers for Independent Living, your state or county departments of social services and vocational rehabilitation, the Visiting Nurses Association, state home health agencies, the Department of Veterans Affairs (for veterans of the armed forces), HMOs, your funding sources, community colleges, and college and university centers of adult education. Offer to pay for your assistants to take courses that are important to your care.

Solving Employment Problems

Although this is not a pleasant topic, employment problems may arise and you have to know what resources you have available to solve them. The following case studies illustrate issues that may arise.

Case Studies

Care Provided by Home Health Care Agency Employees

Sam is a 58-year-old man with quadriplegia who is dependent on a ventilator. He has personal assistance services 7 days a week, 24 hours a day. This team of assistants is provided by a home health-care agency, which also provides access to a nurse and a social worker to assist in conflict resolution.

Sam's team has problems that are interfering with his care and endangering his well-being. There is a personality conflict between two of the assistants, and this conflict has resulted in service gaps, and at least one incident has resulted in Sam having to go into the hospital to obtain his care. One of the team members drank alcohol while on the job. Sam also claims that certain team members have been physically and verbally abusive with him.

Sam consulted with the nurse case manager and reported the issues. The nurse case manager called a team meeting with all the personal assistants. The agency social worker was also included to assist in the meeting.

All of the issues were discussed, and the fact that the issues were resulting in physical endangerment and lower quality of care for Sam was stressed. The personal assistant with an alcohol problem was offered the opportunity to participate in a substance abuse education program that included random testing by the home health agency, if he wanted to continue on the job. The allegations of physical and verbal abuse were investigated and the aides in question were confronted by the home health organization. The aides were removed from the job and later discharged.

Sam's medical and dietary needs were reevaluated. To eliminate the personality conflict issue, the home health nurse coordinated all of the work schedules of each care-team member. A new agreement was written during the team meeting and signed by everyone present.

The advantage of contracting with a home-health agency is that you do not have to resolve all conflict alone. There are representatives from the agency that can assist in all issues.

Care Provided by an Assistant Hired Privately

Michael is a 34-year-old C5 with quadriplegia. He has an assistant for three hours each morning and three hours each evening. Michael advertised in the local paper for an assistant, hired one, and trained him. In addition to his morning and evening care, the assistant also drives Michael to work and home again in Michael's van.

Michael is very pleased with the care he receives, but discovered that the assistant was using his van for more and more personal business and leaving the gas tank empty. Michael decided that he needed to speak to his assistant about this and arranged with the assistant for him to stay an additional hour one evening.

During this meeting, Michael explained his concerns regarding the personal use of his van and then asked the assistant to respond. The assistant said that his personal car has broken down and he needed to use the van. Michael and the assistant were then able to come to an agreement regarding the use of the van, which included a

time frame for the assistant to get his car repaired and payment of gasoline expenses.

**USE THE RESOURCES
AVAILABLE TO YOU TO
RESOLVE CONFLICT
AS SOON AS
POSSIBLE**

Care Provided by Family Member and an Assistant Hired Privately

Pamela is a 62-year-old woman with multiple sclerosis. She has lost the use of both her upper and lower extremities and uses a wheelchair.

Her morning care is provided by an assistant she hired from the roster at the Center for Independent Living in her city. The assistant has been with her for six years. Her husband provides her care the rest of the day.

Her husband has recently noticed bruises on Pamela's arms. He has also noticed that she is not as talkative and seems more depressed over the last month. He asks Pamela about the bruises. Initially, Pamela says her arms were not placed correctly while she was in the chair and she hit the wall. When bruises continue to appear, her husband questions Pamela again.

This time Pamela breaks down and tells her husband that her assistant is responsible, but she is afraid if she reports this and her husband cannot provide the care she needs, she will be forced into a nursing home. Her husband agrees not to report the assistant only if there are no more incidents. Pamela agrees.

Several weeks later, after the assistant leaves Pamela is in tears. Her shoulder appears to be dislocated. Her husband calls 911. Pamela is taken to the emergency room and a social worker is called. The social worker speaks at length with Pamela and then makes a referral to Adult Protective Services. She also calls the Center for Independent Living to report the problem.

Working with the Center for Independent Living, Pamela and her husband are able to find another assistant.



Based on these case studies, you can see that there are a variety of ways to handle conflict and in certain situations you may not have to do it alone. If at any time you feel that you are being physically abused or neglected, you can always contact Adult Protective Services in your area, or call 911 if the threat is imminent.

The most important thing to remember is to use the resources available to you to resolve conflict as soon as possible. Do not let an unpleasant or potentially dangerous situation go on indefinitely. The upcoming sections deal in more detail with specific tips and potential conflict issues.

Prepare Yourself to Deal with Conflict

Some, if not most, employer/employee relationships go on for a long time with minimal difficulties, but even in the best of situations, conflict may arise from time to time. After all, when two people are together, their own differences may automatically cause some occasional conflict. Problems between you and your personal assistants will be more serious and frequent if your relationship is based on unshared assumptions. As we discussed earlier, having a written letter of employment and detailed checklists to guide the working process will be a great help by clarifying basic issues.

COMMUNICATE YOUR APPRECIATION FOR A JOB WELL DONE ON A REGULAR BASIS

However, rules and agreements can be broken. Then what do you do? If there is a conflict over duties, pay, time off, social conduct, or use of property, discuss these issues with the personal assistant. If you are not satisfied with the outcome of the discussion, you may consider finding another personal assistant rather than continue in a situation that is not desirable for you. If you are dependent on one personal assistant for survival, it may be very difficult to fire that person on the spot and find a replacement. This is another reason why it is important to have an emergency backup plan.

No matter if you have one or several personal assistants, it is important that you have other social relationships. You need contact with family, friends, neighbors, church members, or others so that you do not become isolated and totally dependent on your assistant.

Allowing an undesirable situation to continue may mean that your health may be jeopardized. Do not let things pile up. Deal with each issue as it arises. In cases where you believe that the problem can be solved, you may want to have an advocate help you and your personal assistant settle the disagreement.

Communication Tips

What you say and how you say it are equally important in being understood. Your facial expression, body language, and tone of voice are all part of the message. For example, saying something nice in a negative tone of voice leaves doubt about your intended meaning, because it gives a mixed message. On the one hand, something positive is said, but on the other, your tone of voice or demeanor indicates a negative message. Be straightforward and honest.

Look directly at the person you are talking to. Evasive eye contact may convey a message that you do not want to listen to the person or deal with the issue. Begin the conversation with a positive comment and follow with your concerns. For example, "I like the way you..., but the way you...has become a problem for me."

Perhaps even more important than communicating what is wrong, communicating your satisfaction and appreciation for a job well done on a regular basis will let assistants know they are doing a good job. By focusing attention on what someone does well, you can greatly increase the probability that the good work will be repeated. By giving positive feedback often, you'll let your assistants know that they are doing tasks as you prefer them to be done.

If you believe that the assistant is not hearing (or heeding) instructions, needs, and other messages from you that are necessary for your care, consider putting your messages in writing. Writing down concerns tends to reduce misunderstandings. If your disability prevents you from writing, consider putting your message on tape.

It is sometimes helpful to have a friend or family member present when you discuss issues with your personal assistant so that you have another person available to help you and the assistant to deal with the problems. The family member or friend can also act as a witness in case there are any disputes later on. Do not delay taking on a problem, especially if it relates to your care.

Once a problem is resolved, let it go and move on. Don't hark back to previous issues when dealing with a current problem.

Being assertive is very important. Assertiveness is a skill that can be practiced. It involves asking for what you need without being rude, nasty, or obnoxious. There is a great deal of difference between being aggressive and assertive. Aggressive behavior is negative and can be seen as hostile. Such behavior is likely to get an unfavorable reaction from an individual who feels that you are being rude or hostile. Assertive behavior, on the other hand, recognizes the dignity of both parties and is a respectful, effective, and clear way to interact.

The reference section contains three excellent books on assertiveness. If you only can find the time to read one, read Manuel Smith's *When I Say No, I Feel Guilty*. It is not only informative, but also fun to read.

Assertiveness—How to be in Control

Assertiveness is a combination of behaviors that help people to express themselves and act in ways to stand up for themselves without denying the rights of others.

Assertive people communicate openly and honestly, without guilt and with self confidence.

Behaving in an assertive manner with employees is a particularly important key to effective management of your small business—your personal assistance services system. Assertiveness is a way to express your legitimate rights. If you do not feel that you are assertive, you can learn this skill. Assertive behavior:

- Is honest
- Is direct
- Does not hurt others
- Respects the rights of others
- Is calm
- Gives clear messages
- Enhances your ability to have your needs met
- Means accepting responsibility for your own actions

Remember that you have the right to:

- Your own values and emotions
- Tell others how you wish to be treated
- Say, "I don't know," "I don't understand," or simply, "No"
- Change your mind
- Make mistakes
- Attend to your needs
- Decide how you lead your life
- Ask for help

PRACTICE IS ESSENTIAL TO DEVELOPING NEW SKILLS

When you are assertive, your body language and your voice will show it. Usually, making direct eye contact and using appropriate gestures and facial expressions support your respectful and clearly stated request for getting your needs met. Don't forget to consider the other person's point of view while confidently expressing your own needs.

There are some specific techniques for behaving assertively. Be very clear and specific about what you want done, using "I" statements. For example, say, "I want you to do the dishes, please." (Not, "Those dishes aren't going to do themselves, you know.")

Deliver your messages directly to the other person involved. Don't beat around the bush, but tell the person directly, confidently, and calmly as soon as you can. (If

you wait too long, the message will not have the same impact.) For example, if your personal assistant is giving you a bath and starts with your feet instead of your face, you might say, “You have started washing my feet first. Please, now and in the future, begin with my face. Please get another wash cloth and some fresh water and let’s begin again.” You may wish to explain that you do not want to have your face washed with water that has first washed your feet, so that the cleanest water is used on your face first.

Make sure your message is understood by asking for feedback. “Am I being clear?” “Do you have any suggestions?” “Is this a workable solution?” This encourages your personal assistants to participate in the process and recognizes their importance. You may decide not to change your mind after their feedback, but you will have shown respect by asking for it, listening to it, and considering what was said.

One technique that is very effective in correcting others is the use of “When you . . . , I feel . . . , I want . . .” statements. Suppose an assistant leaves your home to run a short errand, but fails to lock the door. You might say to the assistant, “**When you** don’t lock the door, **I feel** unsafe. **I want** you to always lock the door when you leave, please.” You have pointed out the problem in a nonargumentative way, told the assistant the results of the mistake, and made clear what you want to happen.

Remember that practice is essential to developing new skills. Each time you use assertive behavior effectively, it will reinforce your skill at it and make it easier to do next time. If you are having a problem with your personal assistant, you may want to consider role playing the situation with a friend or family member, to practice your assertiveness. It will be important to remind that person to be objective and that you are interested in suggestions, so that when you speak with your personal assistant there will be a positive outcome.

Some Common Employment Problems and How to Deal With Them

Attendance

Attendance problems can involve tardiness, when an employee is late coming to work, or absenteeism, when an employee does not show up for work at all. When an employee does not report to work for a lengthy time period, it is called abandonment.

Attendance is probably the most frequent complaint that employers make about personal assistants. Attendance issues should be discussed when the personal assistant is hired and should be clearly outlined in the working contract. As a person with a disability, you know the feeling of helplessness and fright that occurs when the person you are expecting to help you does not arrive on time. An assistant who is late or absent will certainly disrupt your schedule at the minimum.

Tardiness may also result in your physical or emotional discomfort. You must be aware, too, that being left without personal assistant services for a lengthy period of time can result in severe danger to you and can lead to serious harm and hospitalization, perhaps even death. Thus, attendance problems, such as tardiness or absence, must be addressed immediately.

The assistant should be made aware of the need for promptness and the importance of maintaining a care routine. Take the time to review the assistant’s schedule and your routine. Ask the assistant if there are any reasons this schedule is not feasible. If the assistant has issues that prevent compliance with the agreed-upon schedule, you may need to make adjustments or begin looking for an assistant who can meet your schedule needs.

In the extreme case of abandonment, a personal assistant who does return should be dismissed immediately. If the abandonment resulted in bodily harm, or if the personal assistant makes threats of bodily harm or against your life, you should immediately call 911 to report it. You may also wish to file an abuse complaint with your local adult protective services agency.

A portion of this issue can be resolved by including guidelines for tardiness and absenteeism in your employment contract. These guidelines should include how many days in advance you want to be notified for time off and how many hours in advance you want to be notified for tardiness. This will at least set down your expectations in the beginning of the relationship.

Once again, these are guidelines. There will be times when you make an exception.

Unsatisfactory Care

There may be times when the person providing care may perform certain tasks in a manner that is either dangerous or contrary to your wishes.

Unsatisfactory care is another issue that should be addressed at the time you hire your personal assistants, and the methods for handling unsatisfactory care should

be clearly written in your employment contract. If unsatisfactory care does occur, you should address it immediately. It is possible that this problem can be solved by making sure that the assistant truly understands the tasks that need to be accomplished and the manner in which you prefer them to be done. This can be achieved by reviewing the job description and contract agreement that you and your assistant signed.

Additional education or training may be required. If you hired your assistant privately, you may need to review the training yourself. It may be possible to have someone that you know is knowledgeable in this area provide additional training. If you hired a home health agency to provide assistant care, contact them immediately and discuss your options for replacement or additional training for your assistant. Check with your health-care provider regarding sources for additional training and resource materials.

If the care does not improve, or if there are more instances of unsatisfactory care, you should give a written warning specifying the problem and a time frame for improvement. Keep a copy of it in the personal assistant's employee file. If the care remains unsatisfactory, then the assistant should be dismissed.

Substance Abuse

Substance abuse is the use of alcohol or drugs that can endanger you and reduce an employee's ability to successfully work.

Alcohol and drug use is another issue that should be clearly addressed in your letter of employment and discussed at the time of hiring. No alcohol or drug use should be allowed during working hours. Such use should constitute cause for immediate dismissal.

If you are using an agency for personal assistants, adhere to their policies on reporting substance abuse. There may be laws in your state requiring an employer to report substance abuse by individuals employed in a health-care setting to health or law enforcement officials.

Under no circumstances should your personal assistant be allowed to drive while under the influence of alcohol or drugs. Not only is this hazardous, it's illegal.

Theft, Property Misuse, or Damage

Stealing your belongings, eating food, using your personal property, or damaging something are all problems that can occur on the job.

In most cases, people are honest and prove to be competent, reliable personal assistants. Occasionally, however, you may encounter theft and property misuse or damage. How these issues will be handled if they occur should be written into your employment contract. Do not hesitate to dismiss someone who has committed theft of property or serious property misuse or damage.

Don't forget that theft and property damage are legal matters, and a police report should be filed. Your insurance company will require this if you file a claim based on theft. You may also wish to press charges if the offense is serious.

Although there is no guarantee against crime, being careful about how you handle your property can usually eliminate many of the problems. Here are some preventive measures you should generally take:

- Never allow your personal assistant access to your cash, unless providing you a shopping service.
- Never allow your personal assistant access to your checkbook unless assisting you with bill paying.
- Never allow your personal assistant access to your credit or debit cards.
- Never leave valuables lying about.
- Always keep your medications under your control.
- Always keep your alcoholic beverages under your control.
- Always keep your vehicle keys yourself unless your assistant provides driving services.
- Check your telephone bill for charges you did not incur.
- If a personal assistant does shopping for you, always check the receipts.
- If a personal assistant ever physically assaults you, call 911 immediately.
- If a personal assistant steals from you, call the police immediately and take steps to discharge the assistant at once.

There will be instances in which the above guidelines cannot be followed. For example, if your personal assistant runs errands for you requiring your vehicle and payment of some sort, it will be necessary to provide your assistant with the keys to your vehicle and enough money for the purchases (never give your debit or credit card). In all cases, you should limit access and monitor for problems.

Personality Conflict

People are different and not everyone gets along. The same can happen with you and an employee. You do not need to be best friends, but you do need to be able to work together so that you get the best care possible.

A personality conflict can result from something as simple as a difference of opinion or a misunderstanding, or it may be a symptom of a more serious problem. Whether or not a personality conflict affects the quality of your care, it should not be ignored. Remember, you and your personal assistant have contracted for a long-term business relationship. The intimate nature of the arrangement makes it even more important to ensure a minimum of disagreement and conflict. If the personality conflict affects the quality of your care, or becomes severe, you should consider terminating the contract and replacing the personal assistant.

Emotional Attachments

This manual has stressed the professional nature of your relationship with a personal assistant. However, it is also a very personal relationship. It may be difficult for one or both parties to deal with the physical intimacy without getting emotionally involved.

One-sided love presents a number of pitfalls. As an employer, you cannot demand that your aide fall in love with you or perform sexual favors. Your assistant is likely to quit, on the spot, and you are opening yourself to charges of sexual harassment. You hire personal assistants for specific tasks and it is unfair to burden them with all of your emotional or sexual needs. It is often difficult to share so many aspects of your life without trying to share

all; that is one of the reasons we stress throughout this manual the need for you to establish and maintain the role of employer.

If your assistant makes advances that are unwelcome to you, you need to assert yourself to keep the relationship on a professional level. While you want to maintain open and friendly relations, you should not allow yourself to be pressured into a degree of intimacy you do not want. You need to protect yourself from sexual abuse, including terminating the offending assistant's employment, if lesser measures fail. As with physical abuse, or the threat of abuse, sexual abuse is a crime. You should report it to the police and to the agency if you use one.

But maybe you both fall in love. Although rare, it does happen. Congratulations on finding someone to share your life with. Now you need to find another personal assistant, because mixing the roles of assistant and spouse can put a great strain on both relationships.



It is important that you feel comfortable with personal assistants. All expectations should be clearly outlined and discussed in the initial agreement that you both sign. If problems arise, talk about them right away and do not let them build to a point where the only possible solution is termination. Usually, little problems do not become major problems if they are addressed directly and solved in the early stages.

Tax Responsibilities

As an employer and consumer you must address tax arrangements for yourself and the personal assistants who provide services for you.

Your Responsibilities When Using an Agency or a Funding Source

If you are receiving funds with which to pay a personal assistant, follow the instructions from the funding source regarding:

- What payment records you must keep.
- In what way and how often you will be receiving this aid.
- What procedures they suggest you use in paying a personal assistant.

The source or agency may insist on obtaining the names and Social Security numbers of personal assistants in order to pay them directly. You may find that the process of a check coming “automatically” to a personal assistant takes away some of your authority with your employee. Also, whenever you change personal assistants, the paperwork and delay in the payroll process can result in an unearned paycheck being sent to your former personal assistant or a considerable delay in the first paycheck being sent to the new personal assistant.

However, many people find the paperwork of being an employer cumbersome and worry about keeping up with changes in employment law. You may prefer to have an agency handle payroll and taxes for your assistants.

Ask your funding source and local tax people whether your particular plan of funding requires any personal assistant you employ to declare the income on federal, state, or city taxes. As a matter of courtesy, inform your personal assistants of any taxes they must pay at the time you employ them.

Your Responsibilities as an Employer

Personal assistants working more than eight hours per week on a regular basis are considered employees and must be paid a minimum wage in accordance with federal law. As the employer, you assume responsibility for

Social Security (FICA) and Federal Unemployment (FUTA) taxes.

Where the consumer is the employer, workers’ compensation coverage is not mandated by federal law. Some states, however, require you to pay state taxes and workers’ compensation. To avoid problems, consult a tax adviser or attorney to see which laws would affect you.

You may wish to reimburse a personal assistant by noncash means. Paying your assistant this way reduces your paperwork and tax costs. You do not have to pay social security and federal unemployment taxes on non-cash wages. However, your assistant may be required to pay federal or state income taxes on noncash wages. In addition, the IRS has specific criteria regarding when and how meals and lodging you provide as noncash wages can be considered medical deductions on your income tax return.

As stated earlier, one of the simplest methods of providing noncash wages is to offer personal assistants room at your home in return for their services. Current IRS rulings imply that the cost of any benefits that are offered to the personal assistant, beyond that which you or your family would need ordinarily, might be medically deductible. For example, if you would normally need a one-bedroom apartment, but you have to rent a two-bedroom apartment for the personal assistant, the cost difference between the one-bedroom and two-bedroom apartment might be deductible.

When you are planning what noncash wages to offer your personal assistant, choose, in priority, those items that you can most easily prove you paid for—those for which you’ll have receipts or other records.

Getting Started

Employer Identification Numbers (EIN)

All employers must have a federal employer identification number (EIN). This is not the same as your Social Security number. If you hire or plan to hire a personal assistant, but do not have an employer identification number, you should apply for one by filing Form SS-4 (Application for Employer Identification Number). You may obtain Form SS-4 by telephoning the IRS toll-free number, (800) 829-1040, or at the IRS website, www.irs.ustreas.gov.

Employee's Social Security Number (SSN)

Every employee must have a Social Security number. As an employer, you must obtain each employee's name and SSN, and enter them on an annual Form W-2, Wage and Tax Statement, which you must give to employees by January 31 of each year. If you do not provide the correct name and SSN, you may owe a penalty. Any employee without a Social Security card can get one by completing Form SS-5, Application for Social Security Card. You can get this form and Form W-2 at Social Security Administration offices or by calling (800) 772-1213.

Federal Income Tax Withholding

You do not have to withhold income tax on wages paid to personal assistants unless they ask you to and you agree. If this is the case, the employee must give you a completed IRS Form W-4 (available at IRS offices, many post offices, and at www.irs.ustreas.gov). You must withhold an amount from each wage payment based on the Form W-4 and tax tables in Circular E, Employer's Tax Guide. You can get Circular E at IRS offices, and at www.irs.ustreas.gov.

Social Security Taxes

One of your main taxpaying responsibilities as a household employer will be paying Social Security and Medicare taxes. (These taxes are referred to as FICA taxes, for the Federal Insurance Compensation Act). You must withhold the employee's share of taxes each time you pay wages, and you must pay an equal amount from your own funds once a year when you pay your federal income tax.

The FICA tax rate changes periodically. Contact your Social Security office to get the most current rate.

Federal Unemployment Tax

The Federal Unemployment Tax Act (FUTA), with state unemployment systems, provides for payments of unemployment compensation to workers who have lost their jobs. This is paid on the employer's income tax return if \$1,000 or more in wages have been paid per quarter.

State Taxes

You can find out what your state requires in relation to employment taxes by calling your state's Department of Labor or Employment.

Self-Employed Workers: The "Independent Contractor"

Some people who employ personal assistants attempt to define them as "independent contractors" rather than "employees" to avoid employment tax responsibilities. It is claimed they are independent contractors who use their own equipment, set their own hours, supervise themselves, and may work for several employers. Independent contractors are responsible for purchasing their own workers' compensation or other insurance coverages.

However, the IRS has very strict guidelines for independent contractors and will consider a personal assistant to be an employee unless you can prove he or she is an independent contractor under the following language:

Anyone who performs services is an employee if you, as an employer, can control what will be done and how it will be done. This is so even when you give the employee freedom of action. What matters is that you have the legal right to control the method and result of the services.

Should the IRS ever question your use of self-employed workers as a possible tax-dodging ploy, the burden of proof—and any penalties—will fall on you, not the personal assistant. For more information on independent contractors, call the IRS at: (800) 829-1040 and ask for Publication 937: Employment Taxes, or call your Social Security office and ask for a free copy of *If You're Self-Employed*.

If you want the IRS to decide your personal assistants' status for you, you may file Form SS-8, Determination of Employee Work Status for Purposes of Federal Employment Taxes and Income Tax Withholding, available at IRS offices or by calling (800) 829-1040.

Tax Deductions and Credits for Personal Assistance Services

Deductions for Personal Assistance Services

Deducting the costs of personal assistance services for tax purposes depends on what kind of work is done. To convince the IRS that personal assistance services are deductible you must prove they are the equivalent of nursing care. If the services are not clearly deductible as a medical expense in nature (for example, part of a prescribed plan of care monitored by a physician), you can

expect questions from the IRS. You should get a statement from your doctor that includes:

- A description of your medical condition, whether it is permanent, and the cause and date of its onset
- A complete list of the help needed
- A statement of whether you need live-in or daily help

These are general guidelines. Contact the IRS office in Washington, DC, at (800) 829-1040 and explain what you are paying and request a letter from them stating what you are allowed to use as a deduction. The use of personal assistance services comes under the section on Tax Laws of Special Interest. Regulations of this code are available at district offices of the IRS. Once you get a letter from the IRS stating what is allowed, file a copy of it every year with your tax return.

In addition, there may be tax credits available to you or your working spouse for expenses related to your care, particularly if you are elderly, low-income, or receiving Social Security Disability Income. Consult a tax advisor for more information about your particular situation.

Keeping Track of Tax and Related Information

You must keep tax-related records for at least 7 years. These should be available for IRS review. Your records should contain:

- Your employer identification number
- Copies of tax returns you have filed
- Dates and amounts of all wage payments you have made
- Copies of each employee's tax withholding allowance certificate (Form W-4)
- Any employee copies of Form W-2 that were returned to you as undeliverable

It is important to have a file card for each personal assistant, even those who may have been employed for only weeks or days. Include the name, address, phone number, date of birth, social security number, driver's license number, date hired, and final date of employment. The name on the file card should be recorded exactly as it appears on the social security card.

Sample Employee File Card

EMPLOYEE FILE CARD	
Employee's Name:	_____
Home Address:	_____
Telephone:	_____
Social Security Number:	_____
Date of Birth:	_____
Start Date:	_____
End Date:	_____
Reason for leaving:	_____

A Summary Chart of Federal Tax Forms Employer of Personal Assistance Services

CASH WAGES

IRS Form	Used Primarily to Report	When Due
W-4	Employee-desired amount of income tax to be withheld from cash wages (for "household employment" tax may be withheld only if both employer and employee voluntarily agree)	At beginning of employment. Each time employee wishes to change withholding status
SS-4	To obtain employer's identification number (EIN)	One number for employer's lifetime. For use when filing various IRS forms
942	a) Cash wages of \$50 or more paid to each employee in any calendar quarter b) Income tax withheld during the quarter c) FICA (Social Security) taxes (about 6% of each employee gross pay amount) withheld from the cash wages of any employee meeting criterion (a) to be matched in amount from employer (attach check for combined tax amount to FICA-942 form)	4 times a year; within 30 days of the end of each IRS-defined calendar quarter (3-month period)
940 & 580 Federal Unemployment Tax	FUTA (unemployment taxes (3.4% of first \$6,000 paid to each employee) to be paid by employer; to household employees, those who paid cash wages of \$1,000 or more during any calendar quarter	1/31 for wages paid in preceding year; file 940 with 580
W-2	a) Cash income to employee b) FICA taxes withheld from employee c) Income taxes withheld (see note for W-4 form regarding household employment). Worker is responsible for paying withholding	1/31 for wages paid in preceding year or within 30 days of employee termination if before the end of year
W-3	To be filed with Copy A of W-2 and sent to Social Security Administration	1/31, with W-2

Each state has different rates. Find out your own state regulations to determine how much and how often to pay these taxes. In some states, nothing is due if wages are less than \$1,000 per quarter.

NONCASH WAGES

IRS Form	Used Primarily to Report	When Due
SS-4	Same as cash wages section.	
W-2	Value of noncash wages paid.	1/31 for wages paid in preceding year or within 30 days of employee termination if before the end of year

Transportation

Traveling with a personal assistant will require planning, as does any travel. You must be clear with the assistant what his or her responsibilities are, for instance, driving, assisting in transferring in and out of vehicles, or carrying luggage.

For getting around town, most public transit vehicles are now wheelchair accessible. Many public transit systems permit a personal care assistant to ride free of charge—in fact, this is a requirement of the Americans with Disabilities Act for people who use paratransit.

When deciding whether to travel with a personal assistant, you must determine your needs both en route and at your destination. When making your arrangements, be certain to ask the right questions. What services can you expect from transportation personnel? Is there a charge for a personal assistant? Do not assume that policies are consistent among transportation providers or that they will remain unchanged. Ask these questions each time you make a reservation.

You may decide not to take your assistant with you when you travel but rather to hire an assistant in your destination city. It is both safer and easier to use a center for independent living or home health agency to locate a temporary assistant, rather than relying on word of mouth. Allow the agency sufficient lead time to identify an aide; call as soon as you know what your travel plans are.

Make sure that both you and the assistant have full information: names, places, telephone numbers, dates, and times. If the aide will be meeting your plane, include the airport, airline, and flight number in the information you give. Be clear what services you will need, where and when you will meet, and how to recognize each other if you are meeting at a public place. If the aide will be coming to your hotel room, you must tell the hotel and give them a name. Hotels will not give out room keys, or even room numbers, of their guests without prior arrangement and identification of the visitor. If you need morning services, it is advisable to meet with the assistant the night before so you can go over the details of what you need and hand over the spare room key.

Air Travel

Under the Air Carrier Access Act, if you require assistance to evacuate the plane in case of emergency, you must bring (and pay for) your own assistant. If the airline determines that you require such assistance, and you disagree, the airline will provide passage for the assistant—but they may choose the assistant, perhaps an airline employee. That person is responsible for assisting only in the case of evacuation. If you do travel with an assistant, the airline must provide you with seats next to each other on the plane. Be aware that airline personnel will not provide personal assistance on the plane. They will help in boarding, information, stowing luggage, and helping you get to and from the bathroom; they will not assist within the bathroom or with eating.

You can get more information about the Air Carrier Access Act by ordering *New Horizons—Information for the Air Traveler with a Disability* by writing to:

Department of Transportation
Aviation Consumer Protection Division, C-75
400 Seventh Street, SW
Washington, DC 20590

You can also find this brochure at the Department of Transportation's Accessibility Home Page at <http://www.dot.gov/accessibility>

Amtrak

Amtrak has a special discount program for rail passengers with disabilities that may offer discounts for personal assistants as well. Amtrak personnel will help with boarding, information, and at-seat services such as delivering meals, stowing luggage, and getting to and from the bathroom. They will not assist in eating, personal hygiene, or providing medical services en route.

Amtrak's publication *Access Amtrak* will inform you of Amtrak services for travelers with disabilities. To receive this publication:

- **Call** their customer service line at:
(800) USA-RAIL or (202) 906-2500 TTY
- **Write:**
Office of Amtrak Access 2W
60 Massachusetts Ave., NE
Washington, DC 20002

- **Visit:** their website at:
www.amtrak.com/trip/special.html

Greyhound

Assistance is available from Greyhound to passengers with disabilities. Call Greyhound Lines' ADA Assist Line at (800) 752-4841 at least 48 hours before your departure to arrange for the proper assistance along your route. You will be asked for information to help Greyhound personnel provide the assistance you need. If you cannot provide prior notification, Greyhound will make every reasonable effort to accommodate you without delaying bus departure schedules.

With some restrictions, personal care assistants may travel free on Greyhound. The ADA Personal Care Attendant ticket will be issued only to the personal care attendant, only at the time of travel, and only for one-way. You must obtain a return ticket for your assistant from the returning location on the day of travel. Your assistant must be capable of providing the assistance you require.

If an adult assistant is traveling at no charge with a minor who has a disability, the minor is charged a full adult fare. Call Greyhound ADA Customer Assistance at the Greyhound ADA Assist Line at (800) 752-4841 for information regarding restrictions on minors traveling with disabilities.

- **Call:** (800) 752-4841
- **Visit:** their website at:
www.greyhound.com

More General Information

For more information on the Americans with Disabilities Act, please call PVA's publication distribution center at (888) 860-7244 and ask for The ADA—Your Personal Guide to the Law. You can also find this brochure, as well as The Air Carrier Access Act—Make it

Work for You at www.pva.org under "Living with SCI: Advocacy."

Travelin' Talk is a global network of people with disabilities. They share knowledge about their hometowns or extend a hand to other members of the network who are visiting or passing through. You must join the network to get information from them, which includes a monthly e-mail newsletter and a directory of members on a secure site on the web. You can reach them on the internet at www.travelintalk.net.

Other websites that are helpful for travelers with disabilities include:

- <http://www.access-able.com>
- <http://www.projectaction.org/paweb/index.htm>

This last site contains information about accessible public transportation in many locations around the United States.

Finally, the key to success in any traveling you do is good planning. Work with your assistant to develop a travel plan that covers all aspects of your personal needs, e.g., comfortable clothing, time requirements, proper bowel and bladder scheduling, meals, transfer techniques and tools, who (such as airline personnel) might need information, and easy access to medication. Make your travel plan part of your trip and you will be happy you did.

Conclusion

For more than fifty years, the Paralyzed Veterans of America (PVA) has been fighting to overcome barriers to independence encountered by people with severe disabilities. Disabling conditions, whether from injury, disease, or aging, force people with disabilities to seek assistance from others to do the daily activities they would do for themselves were it not for their condition. However, for individuals with disabilities, the process of finding, managing, and retaining a dependable personal assistant remains a major barrier to independent community living. The goal of this document is to improve the management skills of people with disabilities and thus enable them to recruit, interview, hire, train, manage, and, if necessary, fire, a personal assistant.

Independent community living does not come easy for people with severe disabilities. However, alternatives such as nursing home care, or receiving assistance from a loved one, can reduce your freedom, stress relationships, lower self-esteem, and contribute to depression. The challenges of self-directing your own paid personal assistant are many but the rewards can be great. It is PVA's hope that the suggestions contained in this consumer guide will help all people with disabilities enhance their independence and improve the quality of their lives.

Remember, good personal assistant management skills are something you can learn. To be successful, remember these few basic hints:

- Make sure you have back-ups in case your personal assistant leaves, gets sick, or has an emergency.
- Communicate your needs and wants in an assertive manner.
- Give your personal assistants lots of feedback so they learn how you like things done.
- Treat your personal assistants with respect.
- Tell your personal assistants “thank you” and that you appreciate them.

The management of your personal assistants means a more independent lifestyle for you. It also means less stress and more time to enjoy your life.

References

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Smith, Manuel. *When I Say No, I Feel Guilty*, Bantam Books, New York: 1975.

Yes, You Can! A Guide to Self-Care for Persons with Spinal Cord Injury. Edited by Margaret C. Hammond, M.D., Robert L. Umlauf, Ph.D., Brenda Matteson, Sonya Perduta-Fulginiti, M.S.N. Washington, DC: Paralyzed Veterans of America: 1993.

Appendix

Sample Needs Assessment Work Sheet

Sample Consumer Preferences Work Sheet

Sample Live-in Assistant Preferences Work Sheet

Sample Personal Assistant Job Description

Sample Telephone Screening Form

Sample Application for Employment—
Personal Assistant

Sample Reference Check Work Sheet

Sample Letter of Employment

Sample Personal Assistant Time Card

Sample Performance Appraisal: Personal Assistant

Sample Personal Care Checklist for
Morning Routine

Sample Employee File Card

Sample Needs Assessment Work Sheet

Need	Frequency	Time Needed	AM	PM
ADLs				
Bathing				
Dressing				
Grooming (shaving, hair care, makeup)				
Meal preparation				
Eating				
Bowel care				
Bladder care				
Turning in bed				
Transferring				
Other:				
IADLs				
Washing dishes				
Grocery shopping				
Turning on computer				
Setting up equipment				
Making bed				
Charging wheelchair batteries				
Driving van				
Errands				
Writing letters				
Answering phone				
Laundry				
Putting away items				
Housecleaning				
Child care				
Pet care				
Other:				
Medical-Related Care				
Pressure relief/positioning				
Medications				
Range of motion exercises				
Skin inspection				
Suctioning, respiratory care				
Other:				

Sample Consumer Preferences Work Sheet

Preference	Absolutely Essential	Very Important	Would Be Nice
Morning person			
Night person			
Able to lift			
Always on time			
Male			
Female			
Nonsmoker			
Nondrinker			
Older person			
Younger person			
Good cook			
Computer literate			
Veteran			
Primary language (English, Spanish, etc.)			
Animal lover			
Drives own car			
Sense of humor			

Sample Live-In Assistant Preferences Work Sheet

Preference	Absolutely Essential	Very Important	Would Be Nice
Temperature comfort range			
Degree of neatness			
Taste in music			
Television viewing			
Talkativeness			
Amount of companionship			
Telephone use			
Kitchen use			
Laundry use			
Visitors			
Pets			
Drug/alcohol use			
Shared expenses			
Car usage			

Sample Personal Assistant Job Description

Summary of Work:

The personal assistant will provide valuable supportive services to a person with physical disabilities.

Qualifications:

- Must be dependable, drug and alcohol free, and able to follow directions
- Must have current immunizations, TB test, and hepatitis B vaccine
- Should have basic first aid training and CPR certification
- Should be able to lift 100 pounds
- Must have a state driver's license
- Must have a Social Security number or a permit to work in this country

Duties:

The duties of this job include but are not limited to:

- Personal care services such as bathing, skin care, shampoo, grooming, caring for the teeth, helping in and out of bed, and assistance with medications
- Assistance with bowel and bladder care by performing catheterization, emptying catheter, and changing colostomy drainage bags
- Assistance with transfers, range of motion exercises, and other activities to increase muscle strength, self-care, and independence
- Housekeeping (vacuuming, cleaning bathroom, making bed, etc.)
- Shopping, grocery and personal
- Driving on occasion
- Participation in in-service education programs on aspects of the disability of the employer
- Animal care

Schedule:

Be available to work Monday through Friday 7:00 to 9:30 a.m. and 6:30 to 9:00 p.m. Occasional work on weekends may be required.

Salary

\$6.00–\$8.00 per hour, depending on qualifications and experience. Room and board available.

Sample Telephone Screening Form

Name of applicant: _____ Date of call: _____

1. Are you available to work on [DAYS OF WEEK] _____

at these hours _____ AM _____ PM **Yes No**

If additional hours were needed on other days, would you be able to fill in? **Yes No**

Are there any days and times you are absolutely unavailable?

2. Can you perform the following duties:

Assisting with bathing	Yes	No
------------------------	------------	-----------

Assisting with personal care (dressing, hair and nail care, shaving)	Yes	No
---	------------	-----------

Assisting with eating	Yes	No
-----------------------	------------	-----------

Cooking	Yes	No
---------	------------	-----------

Cleaning house	Yes	No
----------------	------------	-----------

Shopping	Yes	No
----------	------------	-----------

Wheelchair maintenance	Yes	No
------------------------	------------	-----------

3. If you are given training, would you be willing to perform the following duties:

Inserting and changing catheter	Yes	No
---------------------------------	------------	-----------

Assisting with bowel care	Yes	No
---------------------------	------------	-----------

Assisting with transfers	Yes	No
--------------------------	------------	-----------

Assisting with range of motion exercises	Yes	No
--	------------	-----------

Assisting with skin care and inspection	Yes	No
---	------------	-----------

4. Do you have the following documents?

Proof of citizenship or work permit	Yes	No
-------------------------------------	------------	-----------

Proof of address	Yes	No
------------------	------------	-----------

Social Security card	Yes	No
----------------------	------------	-----------

Driver's license	Yes	No
------------------	------------	-----------

5. Have you done this type of work before?	Yes	No
--	------------	-----------

6. Please give three references:

Sample Application for Employment: Personal Assistant

Application for Employment: Personal Assistant

(Please Print)

Name (last, first, middle initial): _____ Date: _____

Street Address: _____

City _____ State _____ Zip _____ M F

Telephone number () _____ Social Security No: _____

EDUCATION (circle one): Less than High School High school or GED Some college College degree

Currently attending school: (give name) _____

Expected graduation date: _____

If you are under 18 years of age, can you provide required proof of your eligibility to work?Yes No

Are you prevented from lawfully becoming employed in this country because of visa or immigration status?Yes No

Proof of citizenship or immigration status will be required upon employment.

On what date would you be available for work? _____

Can you travel occasionally if the job requires it?Yes No

Have you ever been convicted of a felony?Yes No

If Yes, please explain: _____

Describe any special training or skills: _____

State any additional information you feel may be helpful in considering your application: _____

Are you fully capable of performing in a reasonable manner, the activities involved in the job for which you have applied? A description of the activities involved is attached.Yes No

EMPLOYMENT EXPERIENCE

Please start with your present or last job. You should include any military or volunteer work which may be job related.

(over)

Sample Application for Employment: Personal Assistant – *continued*

EMPLOYER 1.

DATES EMPLOYED: FROM _____ TO _____

WORK PERFORMED _____

Name: _____

Address: _____

Job Title: _____ Supervisor/Phone No. _____

EMPLOYER 2.

DATES EMPLOYED: FROM _____ TO _____

WORK PERFORMED _____

Name: _____

Address: _____

Job Title: _____ Supervisor/Phone No. _____

EMPLOYER 3.

DATES EMPLOYED: FROM _____ TO _____

WORK PERFORMED _____

Name: _____

Address: _____

Job Title: _____ Supervisor/Phone No. _____

EMPLOYER 4.

DATES EMPLOYED: FROM _____ TO _____

WORK PERFORMED _____

Name: _____

Address: _____

Job Title: _____ Supervisor/Phone No. _____

REFERENCES:

1. Name: _____ 3. Name: _____

Phone #: _____ Phone #: _____

Address: _____ Address: _____

2. Name: _____ 4. Name: _____

Phone #: _____ Phone #: _____

Address: _____ Address: _____

I certify that all answers given here are true and complete to the best of my knowledge. I authorize investigation of all statements contained in this application for employment as may be necessary in arriving at an employment decision.

Signature of Applicant

Date

Sample Reference Check Work Sheet

Name: _____ Date: _____

Reference: _____ Tel. #: _____

How long known? _____

Relationship? _____

Reliability? _____

Promptness? _____

Honesty? _____

Driving record? _____

Ability to get along with others? _____

Strengths: _____

Limitations: _____

Good at this type of work? _____

Able to handle stress? _____

For employers:

Start date? _____

Termination date? _____

Reason for termination? _____

Salary? _____

Attendance record? _____

Dependable? _____

Work independently? _____

Reaction to supervision? _____

Reaction to criticism? _____

Duties? _____

Rehire? _____

Recommended? _____

Sample Letter of Employment

September 30, 1999

P.A. Doe
Any Street
Any Town, ST 12345

Dear P.A. Doe:

This letter offers you a job as live-in personal assistant to me, I.M. Theboss, under the following conditions of employment, hours of work, compensation, and general responsibilities. Refer to the attached job description for details of duties.

The work schedule will be Monday through Friday, from 6:30 to 8:30 a.m. and from 5:30 to 7:30 p.m. As needed, you will accompany me on an outing (theater, movie, concert, etc.) approximately one evening per week, to be negotiated on an individual event basis. I will pay all expenses for such outings, as well as for your time.

Compensation will be at the rate of [S?.??] per hour paid weekly on Friday afternoons. You need to complete and give to me an IRS form W-4, with your withholding information. I will withhold federal and state income taxes and FICA (Social Security) taxes weekly. I will give you a form W-2 for your use in filing your income tax statement annually.

In addition, you will have the use of the second bedroom in my apartment, plus access to the laundry room and the storage bin in the basement. The only utility bills you will be responsible for are long-distance phone calls and, if you wish to have a television in your room, the cable hookup and monthly bill. I will pay all other utility bills. My van is equipped with hand controls and other special equipment and is not available for your use.

Except for emergencies, both you and I must give at least two days advance notice in the event of a planned absence. In an emergency, notification must be given as soon as possible.

Theft or unauthorized use of my property, any use of controlled substances, use or being under the influence of alcohol during working hours, or endangerment of my health or safety, will result in termination. We each agree to give two weeks notice of termination for other causes.

My apartment building is a no-smoking environment. It is a condition of my lease that I do not smoke or permit smoking by anyone else in my apartment or any portion of the premises. Since violation of this policy could endanger my lease, this is not a matter for negotiation.

we will cooperate so that tasks required can be completed in a reasonable amount of time. We will respect each other's dignity and privacy. I look forward to a mutually rewarding relationship.

Sincerely,

I. M. Theboss

Sample Personal Assistant Time Card

Time Card

Employee's Deadline: Must be turned in to employer by the first day of the new month.

Employee Name: _____ Month: _____ Year: _____

Day																
Date	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	
Start Time																
End Time																
Start Time																
End Time																
Hours Worked																
Holiday																
Sick Leave																
Annual Leave																

TOTAL:

Day																
Date	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Start Time																
End Time																
Start Time																
End Time																
Hours Worked																
Holiday																
Sick Leave																
Annual Leave																

TOTAL:

I certify that the number of hours shown above is a true and accurate account of the time worked for the month.

Employee Signature

Date

Sample Performance Evaluation: Personal Assistant

Application for Employment: Personal Assistant

Name: _____ Date: _____

Period of Evaluation: _____

RATING SCALE:

- 5 -Far Exceeds** (Performance is exceptional. Initiative and commitment are never in question, even under the most challenging circumstances)
- 4 -Consistently Exceeds** (Performance consistently exceeds job requirements. Meets challenging work goals and independently takes on tasks)
- 3 -Fully Meets** (Performance meets and occasionally exceeds job requirements. Individual skills, initiative, and judgment are being used appropriately)
- 2 -Minimally Meets** (Performance is barely satisfactory. Sometimes requires repeated instruction)
- 1 -Unsatisfactory** (Overall performance is below minimum standards due to inability, lack of interest, or other factors. Immediate improvement is needed or employment may be terminated)

EVALUATION FACTORS:

Job Knowledge – *Knows techniques, methods, and other information applicable to the duties of this job.* Rating: _____

Attendance/Punctuality – *Adheres to job schedule.* Rating: _____

Quantity/Quality of Work – *Is thorough, accurate, and complete in performing tasks.* Rating: _____

Communication – *Understands written and verbal instructions.* Rating: _____

Cooperation and Interpersonal Skills – *Works well with others; accepts assignments and supervision.* Rating: _____

Initiative and Creativity – *Starts and completes tasks independently, suggests new ideas.* Rating: _____

Overall Performance Rating: _____

TRAINING PLAN: List any training needs for the upcoming evaluation period.

EMPLOYER SIGNATURE: _____ **DATE:** _____

I have read this evaluation and discussed it with my employer.

EMPLOYEE SIGNATURE: _____ **DATE:** _____

EMPLOYEE COMMENTS:

Sample Personal Care Checklist for Morning Routine

Personal Care Checklist

Getting Ready

1. Get clothes ready
2. Prepare bath water
3. Check bathroom temperature
4. Make sure needed materials are available

Routine

1. Assist with bladder catheterization
2. Assist with bowel by inserting suppository and digital stimulation
3. Assist in clothing removal
4. Move from bed to bath
5. Wash and rinse body
6. Assist with hair care
7. Move from bath to dressing area
8. Dry body thoroughly
9. Conduct skin check for pressure sores
10. Apply lotion or powder
11. Apply deodorant
12. Shave
13. Assist in dressing
14. Move to wheelchair
15. Assist with tooth brushing
16. Move to breakfast area

Clean Up

1. Put away all materials
2. Clean and disinfect bladder and bowel care materials
3. Clean bathroom

Sample Employee File Card

EMPLOYEE FILE CARD

Employee's Name: _____

Home Address: _____

Telephone: _____

Social Security Number: _____ Date of Birth: _____

Start Date: _____ End Date: _____

Reason for leaving: _____



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