

ACCEPTING THE NEED FOR HELP

When one member of the family becomes disabled, roles within the family change and it hurts. A person who is used to taking care of the family or being the income-provider may become dependent while another person in the family takes on added, often unfamiliar responsibilities. For a single person, the changes may involve unexpected dependence on non-family members. Just the word "dependence" can trigger unpleasant feelings. People who can talk openly about their fears, anxiety, frustration, and doubts will be more able to deal successfully with these new circumstances.

An exacerbation left Holly with loss of vision in one eye, bladder dysfunction, and weakness in both legs. Holly and her husband, Bob, were confronted with the issue of home care. Initially, Holly was adamantly opposed to hiring anyone to help her at home. She feared that she would lose her privacy. She felt confident that she could continue to perform basic tasks. Her only need for assistance, she claimed, was to have someone drive her to stores to do shopping.

Her husband wondered how she could keep the house clean, get to her doctor's appointments, and coordinate the schedule for the visiting nurse and physical therapist. He was also apprehensive about how Holly would manage the nights he was away on business trips.

The prospect of hiring an in-home attendant also posed the question of whether Holly and Bob could afford it. Both of them felt overwhelmed at the prospect of identifying the help needed, interviewing people, and paying the fees.

The first thing Holly and Bob learned was the importance of communication. Holly's fears about her independence and privacy, for example, had to be heard and understood by her husband before they could proceed. And Holly had to listen to his concerns about her safety and other issues she was not even considering. He did not want to crush her

could not ignore her weak legs and poor vision. They both had to plan for the present.

hope of recovery, but he



National Multiple Sclerosis Society

DO YOU NEED A NURSE, AN AIDE, A HOUSEKEEPER, OR A FRIEND?

Before considering who to hire, your present needs have to be identified. Needs usually fall into five general categories: Medical (bowel and bladder management, range-of-motion exercises, occupational therapy); Personal care (bathing, dressing, shaving, toileting, transferring, hair care, meal preparation, wheelchair and scooter maintenance, transportation); Homemaking (shopping, errands, house cleaning, laundry, household paperwork and bill paying); Companionship (conversation, safety issues, entertainment); Psychological (counseling to address depression and assist in developing new goals).

You and your family members should identify the needs together and discuss how they can be met. For example, a nurse may be needed to irrigate a catheter or administer certain medications. An aide can do range-of-motion exercises and assist in morning bathing. The person with MS may be able to prepare meals but not clean up afterwards. A housekeeper can do the laundry but not give a shampoo.

Can a family member, friend, or volunteer be relied on for some needs? Are there times when the person with MS prefers to be alone? Could a "life call" system alleviate some worries about safety? It usually takes time to clarify who is needed and how often. Use the "Needs Assessment Worksheet" to work out answers for your situation.

USING AN AGENCY

There are some advantages to using professional agencies. Agencies select trained aides, physical therapists, and nurses. They handle record-keeping, background checks, scheduling and coordinating care, and they bill insurance carriers directly, all of which can lift a burden off an overwhelmed family. Agency administrators are usually familiar with community services and know insurance requirements and limitations.

It may be helpful to use an agency during a crisis or in a period of adjustment.

When looking for an agency, ask:

- Does it work with your insurance company, with Medicare, with Medicaid?
- What services does it provide?
- What needs cannot be met?
- Will the services be provided by the same person each day?
- Does the agency supply references for the professionals it sends?
- Are these professionals bonded?
- What are the fees? Is there a sliding scale? Do they charge for travel time? Is there a minimum number of hours per visit?

- How do the fees compare with those of other agencies?
- Is there a backup system for emergencies, holidays, or sick days?
- How long has it been in business?
- Is it licensed and accredited by appropriate governmental agencies?

Usually agency administrators process claims with Medicare and/or private insurance and the insured is responsible for some co-payment. Agency rates vary, and so do reimbursement formulas. Be sure to make complete comparisons before making your choice. Agencies usually require a prescription for service from your physician.

HIRING ON YOUR OWN

Employing home help personally involves more work, but it also has some advantages. The family has more control over duties, salary, and scheduling. The agreement is developed without a third party. In many cases, it will be less expensive and thus more appropriate for housekeeping needs.

Before going on your own, be sure this is an option for you. Medicare **requires** that certain services be provided by a licensed, certified home-health care agency. Medicare provides 80 percent reimbursement for skilled nursing care and aides, physical therapy, speech therapy, occupational therapy, and medical social services. You **cannot** hire someone on your own for

these services and receive any Medicare reimbursement.

In addition, Medicare does not provide reimbursement for homemaker services, home-delivered meals, or for 24-hour nursing care in the home. All of this may be subject to change. Private insurance will have other restrictions or exclusions. Be sure to check.

CREATE A JOB DESCRIPTION

From your needs list, you and your family should create a job description. Use the "Job Description" worksheet.

The fee you will pay your help is determined by both your available resources and the community's "going rate". Rates vary from community to community. Use resources such as community social services, your Society chapter, and people you respect who have employed help to establish what the going rate is.

Be prepared to keep records. A written record of your employee's work schedule and payments is required for tax purposes and is important to diminish possible conflicts about hours or payments due. If you pay an in-home helper more than \$1,000 a year, you may have obligations to pay state and federal withholding taxes and Social Security. Contact the IRS for information and forms.

CONDUCTING A SEARCH

Let anyone you trust know what you're looking for. The written job description will help make this clear. In addition to your chapter of the National MS Society, contact hospitals, senior centers, community centers, clergy and church organizations, and college employment offices. Try hospital-based schools for nurses, medical technicians, or therapists, as many of these students would like a health-based job. Call the Independent Living Center in your area. And you may want to try organizations such as the Knights of Columbus, Elks, Volunteers of America, and ethnic clubs such as the Hibernian Society.

A newspaper advertisement widens your search. A small local paper is best. Write the ad using your job description and have someone review it before it is submitted. Include job title, duties, salary range, and a telephone number. For your own protection, **omit your name and address**. You might put the same information on a flyer, which can be posted in colleges, churches, temples, and community centers.

SCREENING CALLS

Be prepared to screen responses. Have paper, pencil and a list of questions by the telephone. Before speaking to anyone, clarify for yourself:

- What are your **minimum** requirements?
- What personal qualities are you looking for?

- What are you looking for in references?
- How much and what kind of experience do you expect?
- Can you be flexible about some of the qualifications you desire?
- Does the person have transportation?
- What language does the person speak?
- How do you contact the applicant? (Be sure to ask for a telephone number.)

If the person sounds suitable on the telephone, try to schedule an interview immediately.

INTERVIEWING APPLICANTS

Have a family member or trusted friend with you. If possible, conduct interviews away from your home to protect your privacy. This is a safety issue, but it also helps to have another person's "gut reaction" to your applicant.

Have the written Job Description with you so the applicant is absolutely sure of the requirements. Don't be tempted to omit mentioning chores that might embarrass you, such as changing a catheter bag or helping you bathe. Open discussion is essential to employing someone who will be capable of meeting your needs.

Ask your applicant to fill out the "Applicant" form. This document helps you make your decision and can be useful if you need to replace someone.

WRITE AN AGREEMENT!

Once you and your family have **checked references**, decided whom you are going to hire, set the fee, and determined responsibilities, it is important to write an agreement you both will sign.

WORDS OF CAUTION

It is daunting to invite a stranger into your home and the intimate parts of your life. You and your family can make the situation less anxiety provoking by doing your homework well. Whether you use an agency or hire on your own, consider these cautions:

- Keep track of how much cash you have and where you have put it.
- Keep checkbooks, credit cards, and valuables under lock and key.
- If you need help writing checks, give them out one at a time.
- If an employee shops for you, always get and read the receipts.
- Never give an employee your credit cards. Rely on family members or trusted financial advisors.
- Don't discuss your finances with anyone except family and financial advisors.
- Keep track of your supply of medications by writing down how much you order and when.
- Don't borrow from or lend money to an employee.

Arrange for periodic, unannounced visits by friends or relatives while your employee is on duty.

Arrange a few code words with a close family member. In case of a bad situation, you can telephone for help by saying something like, "It's Nancy's birthday tomorrow."

Worksheets:

Needs Assessment Worksheet

Job Description

Applicant Form

Employment Agreement

Basics: Who does what services at home?

The Personal Care Attendant (PCA)

does bathing, dressing, grooming, toileting, feeding, preparing meals, and does housework, laundry, household management, and driving—on a daily and long-term basis. In some states, Medicaid may pay for PCAs via independent living programs. Most people hire and pay for a PCA on their own.

The Home Health Aide (HHA) or Certified Nurse Assistant (CNA)

provides limited personal care, assistance with activities of daily living, light housework, a client's laundry, and shopping. HHAs may be covered by Medicaid, Medicare, or private insurance, but rarely for routine care over a long period (which is referred to as maintenance care). The HHA is usually employed by a home-health agency and works under that agency's supervision.

A Homemaker or Housekeeper does housework, cooking, errands, laundry, shopping, and similar chores. Homemakers do not usually provide any "hands-on" or personal services, but they can be hired through a home-health agency as well as a domestic-service agency or privately. Their services are not covered by any medical insurance, either public or private.

Professional services include nursing, physical therapy, occupational therapy, social-work service, nutrition (meal planning, not meal preparation), and others. A doctor's prescription is usually necessary. Medicaid, Medicare, and private insurance usually cover some or all of professional services but frequently with restrictions regarding the number of visits and/or the needs to be covered.

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

nationalMSsociety.org

For Information: 1 800 FIGHT MS

(18003444867)



National Multiple Sclerosis Society

Needs Assessment Worksheet

only be met by a trained person. Keep in mind that needs will change as your condition changes. Reassess from time to time. Then fill in names. You may have more than one name for some needs. Be very specific regarding medical needs as some can Use this worksheet as a tool to help you and your family identify your needs and how they will be met. Sort out needs first.

List of Needs	Who	Who Will Help				
	Self	Self Family Member	Friend (Volunteer)/ Companion (Paid)	Housekeeper/ Homemaker	Health Aide	Nurse/ Therapist
Housekeeping						
Laundry						
Dust furniture						
Vacuum						
Make beds						
Meal preparation						
Dishwashing						
Record keeping						
Errands						
Grocery shopping						
Companionship						
Reading						
Letter writing						
Hobbies						
Safety						

Needs Assessment Worksheet

List of Needs	Who	Who Will Help				
	Self	Self Family Member	Friend (Volunteer)/ Companion (Paid)	Housekeeper/ Homemaker	Health Aide *	Nurse/ Therapist
Medical Care (examples: injections, cath	es: inje	ections, catheter care,	eter care, physical therapy)			
* A Health Aide employed by a home	emplo.	yed by a home health ager	health agency can provide medical services only under supervision of a nurse.	ervices only under s	upervision of a	ı nurse.
Personal Care						
Bathing						
Dressing						
Hair care						
Nail care						
Bowel program						
Bladder program						
Exercises						
Transfers						
Transportation						
For self—weekdays						
For self—weekends						
For children/others						
—weekdays						
For children/others						

Job Description

structions: Do a working copy first, so you have time to think through the details and tinput from others in your household.
. Job Title: This should reflect the major emphasis of the job. Personal care? Housekeeping? Other? Be flexible.
List of major duties: Spell out what you need. You may think mopping and vacuuming is "light housekeeping" while someone else thinks "light housekeeping" means tidying up. Do you plan to go shopping yourself with someone to drive and carry for you? Or do you plan to send your helper with money and a list? Remember, "assist in shopping" could mean either one.
Personal-care issues also need specifics. Do you need help using the toilet? Do you bathe alone but need help transferring in and out of the tub? Use your Needs Assessment Worksheet as a reference.

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1	Requirements: Include all your personal "must have's" such as a driver's license, able to lift 150 lb. person, willing to be bonded. Also list language needs, smoking preference, and if you have pets or children.
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I d	Experience desired: Think through how much direction you feel willing or able to give Don't discourage the right person by making requirements too high. On the other handon't discount the value of experience. Do you want someone with First Aid certification training in transferring? (When you check references, ask about experience your pplicant claims.)
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Applicant Form

(Make copies for use when interviewing a job applicant.)

		SS#
	I	Telephone Day: Night: Cell:
Previous Employe	rs/Experience	
References (must Name	list 3) Telephone	Relationship
Name	Telephone	Relationship
	Telephone	Relationship
Name	1	
Name		
Name Comments		

Employment Agreement

The purpose of the agreement is to confirm the terms you and your employee have established. It is not a legally binding contract. It is a tool to maintain clarity in the relationship. You might want to re-examine it monthly and make changes that feel right for both of you.

			tle:	
Specific Du	uties			
Hours				
М	T	Wed	Thurs	Fri
Sat	Sun	Holiday I	Policy:	
Payment		Paymen	t Schedule	
			For example, every	Friday at end of day.)
			-	
For examp	•	byee; for example,	age, visitor policy. Al	so list personal er Friday at 4:00.")
(For examp	le, your smokin ts of your emplo	oyee; for example,	"must leave every oth	so list personal er Friday at 4:00.")
(For examp	le, your smokin ts of your emplo	oyee; for example,	"must leave every oth	so list personal er Friday at 4:00.")