

Chapter 2

“Before I was diagnosed with MS, I was so busy with the details of just living my life. After my diagnosis, I learned a lot about myself...who I was...what was truly important to me...how I could make do with less. I’ve gained perspective I never had before—I wish I could keep that but drop the MS.”

—Darius, diagnosed in 1990

By now, you may have gathered the information and documents that were suggested in Chapter 1. You also may have set up a support network of friends and family. But now what? You still may have unanswered questions, such as:

- Will I be able to keep my job?
- Will I be able to change jobs?
- Will I need to hire someone to help me at home?
- Will I be able to stay in my current home?

This chapter will help you answer those questions and find ways to view MS not as a wall to stop you, but as a hurdle to clear.

Helpful Organizations

NMSS and PVA both offer a number of helpful publications, and each has a Web site (www.nationalmssociety.org and www.pva.org). Many of their publications can be obtained through local chapters, are available online, or can be ordered for little or no charge. The Resources section at the end of this booklet lists other useful publications and Web sites.

In addition, the PVA and NMSS Web sites can put you in touch with local chapters and support groups. This is an excellent way to learn more about MS, tap into local resources, and share your experiences with others who have the disease.



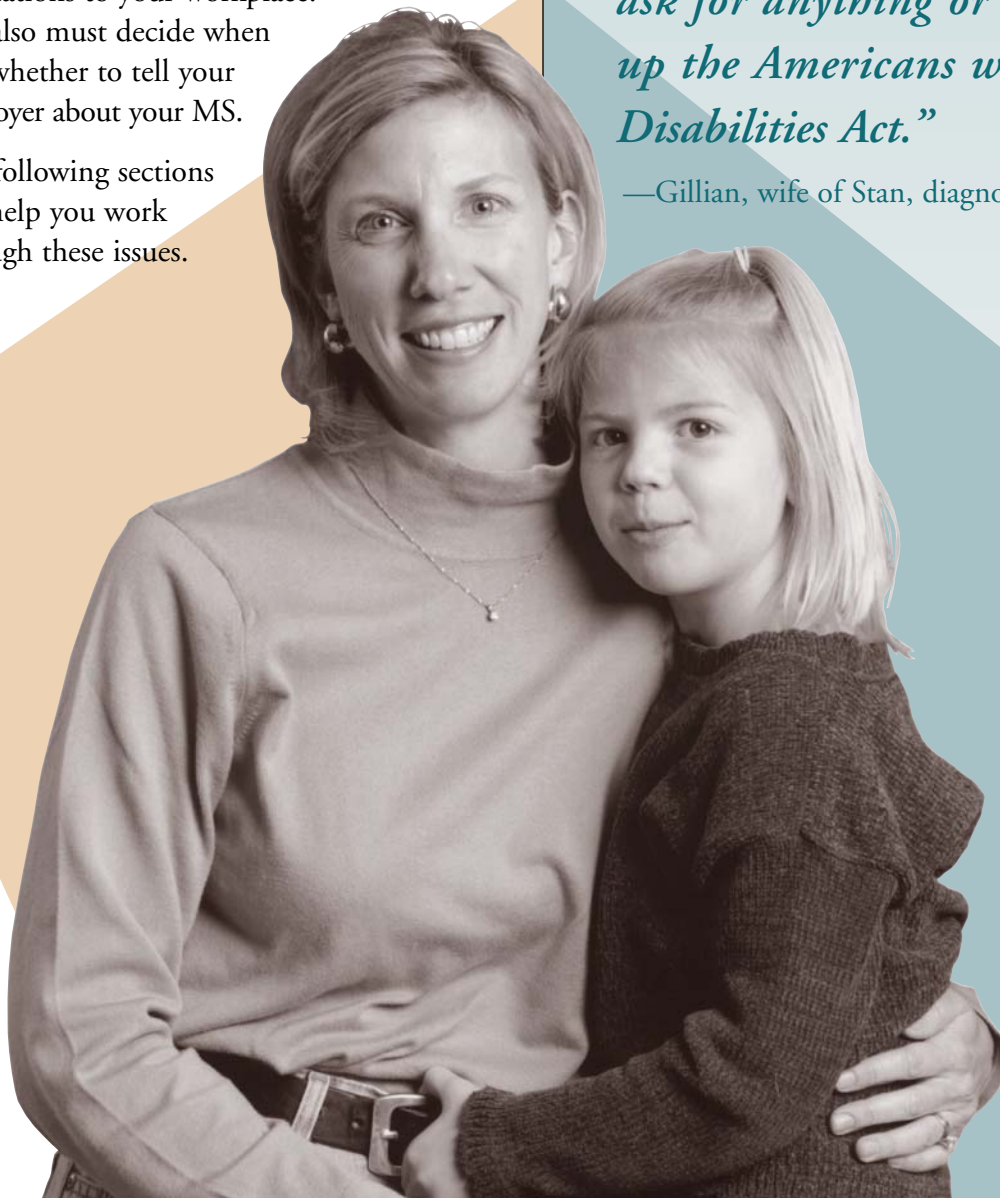
Employment Issues— Current Employer

People with MS often continue to work long after the illness manifests itself. Keeping a job and maintaining a career aren't always easy tasks, of course. You will have to monitor your symptoms and perhaps make special adaptations to your workplace. You also must decide when and whether to tell your employer about your MS.

The following sections will help you work through these issues.

“My husband’s boss was incredible after he learned about Stan’s MS. He provided everything Stan needed to set up an office at home. We didn’t even have to ask for anything or bring up the Americans with Disabilities Act.”

—Gillian, wife of Stan, diagnosed in 2001



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What Makes the Difference?

Some people with MS remain productively employed, while others with similar levels of disability do not. According to NMSS, certain factors appear to be related to job retention, including:

- Basic knowledge of MS
- Knowledge of employment rights
- Symptom management through medications and therapy
- Use of assistive devices and workplace accommodations
- Career planning based on expert advice rather than the well-meaning but often uninformed advice of family, friends, and co-workers



Continuing to Work

If you and your doctor agree that you can keep working, try to do so. For most people, work is about more than a paycheck and benefits (such as health-care coverage). Work also provides interaction with other people, a sense of accomplishment, and a source of self-esteem.

Keep in mind that depression is a common MS symptom. Depression certainly can be the result of the chemical changes happening in the brain because of MS. However, depression also can occur when a person feels isolated, or when the weight of living with a chronic disease becomes too great. A job may help fight these feelings.

Still, your MS symptoms may require changes in how you perform your job. For example, you may need to take more frequent breaks, reserve a parking space near your office building, or change the way you do your job. These changes, called “reasonable accommodations” under the Americans with Disabilities Act (ADA), are discussed in greater detail later in this chapter.

Tip: Avoid making important decisions about work—or anything else—if you are in the middle of a serious flare-up. Symptoms can color your judgment. Wait until you feel better.



Deciding Whether to Tell an Employer About MS

The decision whether to tell an employer about MS is a very personal one. You do not have to disclose the specific diagnosis of MS unless you choose to do so, but there may be reasons to consider telling your employer about your symptoms or disability:

- Some MS symptoms, such as blurred vision or lack of balance, may be mistaken for drug or alcohol problems.
- You may need additional time off for doctor visits or for recovering from flare-ups. Your employer will want to know why you are absent so often.
- You may have difficulty in performing your job because of MS symptoms. In this case, it may be a good idea to explain the situation to your employer before he or she takes any disciplinary action.
- If you decide to apply for employer-paid disability benefits, your employer must know about your MS.

- The laws that help protect you from job discrimination, such as the ADA, generally apply only if your employer knows that you have a disability.

If you do decide to tell your employer, spend some time explaining your MS symptoms. (See “My MS Journal” in Chapter 1.) For example, if your symptoms are more cognitive than physical, your employer may not understand why you can look well, but have trouble remembering instructions. Few people understand that MS also can involve these “invisible” symptoms.

In addition, keep records of talks with your boss or people in the benefits office, and keep copies of your performance reviews. This information will come in handy if you ever feel you are being treated unfairly at work.

Leaving Work Temporarily

Flare-ups can make working impossible, at least for a while, and you may need to leave your job temporarily. There are several resources to help you cope with leaving—and then returning to—your job.

Sick Leave and Vacation

Your employer may allow you a number of days off—with pay—to recover from an illness. Sick leave is useful, but the time off usually is limited to about five to 10 days per year. Also, if you miss work for several days, your employer may want to know the nature of the illness and when you expect to return. If you prefer not to disclose the diagnosis of MS, you can respond to the employer in terms of the symptoms that have necessitated an absence from work.

In addition to sick leave, consider using paid vacation days to cover a necessary absence from work to recover from a flare-up. After your vacation days have been used, ask your employer if you can take additional days of paid leave you may have accrued or unpaid leave (see below).

Family and Medical Leave Act

The Family and Medical Leave Act (FMLA) of 1993 requires employers with 50 or more workers, and all public/government employers, to provide up to 12 weeks of unpaid leave a year to eligible employees coping with certain family or medical situations. You can take the leave in small increments or all at once to care for yourself or an immediate family member, with the guarantee that you can keep your job and your health-care benefits. Generally, the employer may decide whether FMLA time can be taken in installments.



To be eligible for FMLA leave, an employee must:

- Have worked for an employer that is covered by FMLA,
- Have worked at the company for a total of 12 months, *and*
- Have worked at least 1,250 hours during the past 12 months.

Employers may require employees to provide medical certification supporting the need for a leave due to a serious health condition affecting the employee or an immediate family member. In addition, when intermittent leave is needed for medical treatment, the employee must try to schedule the treatment so as not to unduly disrupt the employer's business.

Short-Term Disability Insurance

You may have disability insurance through your employer or on your own. The insurance might pay you a benefit if you experience either a short-term or a long-term disability that prevents you from working. Long-term disability insurance is discussed in Chapter 4.



Keep in mind that even though an exacerbation is temporary, it can be disabling. Short-term disability insurance can help you through these times. With short-term disability insurance, which usually is available only through an employer, you can qualify for benefits within a few days or weeks of becoming disabled. The benefits can stop after a varied number of months, depending on the policy. Typically, you will be paid about 40 to 60 percent of your wages. You must report the benefit as taxable income if the employer paid the premiums for the insurance.

Understanding the Americans with Disabilities Act

The Americans with Disabilities Act (ADA) of 1990 also may protect you from job discrimination. In general, this law applies to workers in companies that have 15 or more employees. (Federal employees are covered under the Rehabilitation Act of 1973, which has been amended to make its protections similar to those provided under the ADA.)

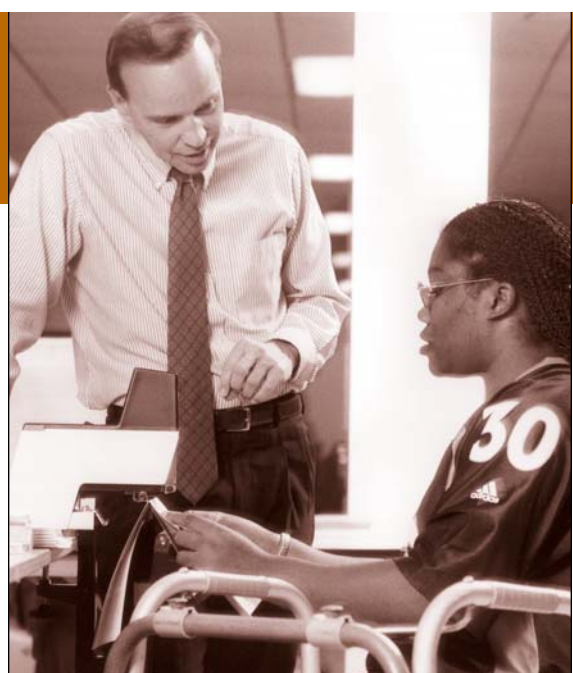
Under the ADA's definition, you have a disability if you have substantial difficulty in performing a major life activity, such as seeing, walking, speaking, doing tasks with your hands, learning, or working in a broad range of jobs.

If this definition applies to you, your employer is required to make a "reasonable accommodation" to allow you to do your job. However, you must be qualified to perform the job, with or without reasonable accommodation. In addition, your employer is not required to make any changes unless you request them.

There is no single definition of what is a reasonable accommodation, but it generally can be defined as a workplace adjustment that compensates for an employee's limitations. The accommodation might be as simple as providing a parking space close to your office. Other examples include a flexible work schedule, a computer keyboard that is easier for you to use, or room at your desk for a special chair.

Employers are expected to tailor changes according to a person's specific needs, but the changes must not cause the employer "undue hardship." Before requesting a change, do some research on what you need and provide a cost estimate, if possible. (Many accommodations cost employers less than \$500, according to the Job Accommodation Network.) In addition, consider talking to your employer in terms of how the change will enhance your productivity on the job, rather than presenting it as a legal obligation.

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Here are some other things to know about your rights under the ADA:

- An employer cannot ask if you have a disability, or how severe it is, unless such inquiry is job related and consistent with business necessity.
- If you need an accommodation, an employer cannot deduct the cost from your pay or ask you to pay for it. If the accommodation would be an undue hardship for the employer, however, the employer must give you the choice of providing it yourself or paying for a share of it.
- A prospective employer cannot ask you to have a medical exam before offering you a job. After offering you a job, the employer can ask you to have a medical exam if all employees in that position are required to do so. Your medical records must be kept confidential.
- An employer must offer you the same health-care benefits offered to other employees, but employers are not required to offer extra benefits to cover your particular medical condition.
- An employer can ask if you are able to perform the essential duties of a job.

- If you have an obvious disability that appears to interfere with performing job tasks, the employer can ask you to describe or demonstrate how you would perform the tasks and whether you need a modification (or accommodation) to help you do them.

The Job Accommodation Network (JAN) can provide more information about job accommodations and working with a disability. JAN is a free service funded by the U.S. Department of Labor, Office of Disability Employment Policy. You can reach JAN at 1-800-526-7234, or visit www.jan.wvu.edu.

Disability and Business Technical Assistance Centers, located across the United States, also provide information about reasonable accommodation. The centers' specialists can answer most questions you or your employer may have about the ADA, and they can research more complex questions if necessary. Call 1-800-949-4232 or go to www.adata.org.

My Plan for Managing My Job

1. This is what I will tell (or not tell) my employer about my MS: _____

2. These are the job accommodations, if any, I will ask for and their estimated costs: _____

3. These are other steps I will take to manage my job: _____

“I was able to get a job after being diagnosed with MS. My boss told me it didn’t matter that I couldn’t move quickly around the office; he needed someone to support people over the telephone. He said he knew I would do a good job—and every day I try to do just that.”

—Candice, diagnosed in 1989



Employment Issues— Changing Jobs

At some point, you may think about changing jobs. Perhaps you feel you no longer can perform your current job because of your MS symptoms. Perhaps you see better opportunities elsewhere. Maybe your employer is cutting jobs because of a sluggish economy. Job changes still are possible after you have been diagnosed with MS, but carefully consider your options before making a decision.

For example, if you generally are satisfied with your employer and benefits, consider asking if you can move into a different job within the same company. This way, you can avoid changing your health-care plan, waiting periods, and so on. If you need to look beyond your current employer, the following sections detail some issues to keep in mind when job hunting.

Looking for a New Job

Here are a few suggestions for job hunting:

- **Focus on what you can do**, not on what you can't do. Make a list of job ideas and write your resume. You do not have to mention your MS in a job resume.

- **Look for a job using the same resources** as people who do not have a disability. These include newspaper classified ads, college career centers, state employment agencies, help-wanted signs in businesses, and Internet sites (try www.usajobs.opm.gov or www.careeronestop.org).
- **Check sources that focus specifically** on helping people with disabilities find jobs. Here are two ideas:
 1. **The U.S. Department of Labor, Office of Disability Employment Policy's** Web site lists employers that have indicated an interest in hiring qualified individuals with disabilities. Go to www.dol.gov. Then click ODEP under DOL Agencies and search for Job Links in the A—Z index.
 2. **State vocational rehabilitation** (VR) agencies help people with disabilities develop job skills and find employment. Services vary by state, and you must apply for them. (If you qualify for Social Security benefits, it is likely that you will be referred to your state's VR agency.) If you qualify for VR services, you may receive job counseling and training, transportation assistance, and special equipment you may need to find and keep a job. Look for a telephone number in the blue pages of the phone directory, or go to www.jan.wvu.edu.



Click Employment Links, then State Vocational Rehabilitation Agencies for a state-by-state list. (Tip: If your first request is turned down, appeal the decision. Show how the assistance can help you get a job and remain self-sufficient.)

3. **VA medical facilities or regional offices** will know about vocational rehabilitation services available to eligible veterans who need job retraining.
- **Decide if you will tell potential employers about your MS.** You are not required legally to disclose your MS during a job interview. This is a personal decision, but NMSS generally recommends that you leave medical information out of a job interview. However, if an accommodation will be necessary, it you will need to mention the symptom or functional condition that requires the accommodation. In short, keep the job interview focused on your experience and qualifications. Help the employer get to know you, not your MS.

Job Changes and Health Care

One of the most important job benefits an employer can offer is a health-care plan. Because MS is a lifelong condition, carefully consider the health benefits provided by an employer before accepting a position. Or, if you currently work for a company that doesn't offer a health-care plan, you may want to look for a new job that has health-care benefits.

In addition to COBRA, the Health Insurance Portability and Accountability Act of 1996 (HIPAA), also known as the Kennedy-Kassenbaum Act, provides protection to individuals with pre-existing condition when moving to a new health plan. HIPAA limits exclusions for pre-existing conditions and prohibits discrimination against employees and dependents based on their health status. This law guarantees that most workers with pre-existing conditions can move from their former group health plan to their new employees plan without a break in coverage. For more information on HIPAA, go to: www.dol.gov/pwba.

Don't ask to see the benefits package during the first interview, but when offered a job, ask to review the package before giving an answer. When reviewing the health-care portion of the employer's benefits package, pay particular attention to the:

- Waiting period
- Pre-existing condition exclusion period (described in Chapter 1)
- Plan benefits and your costs



Waiting Period

Before switching to a new employer's health-care plan, find out *when* the plan will cover you. There could be a 60-day to 90-day waiting period—or you could be covered the first day you report to work.

Try to avoid a gap in your medical coverage. Such a gap could mean facing a pre-existing condition exclusion period. If you have to wait to join a new employer's health-care plan, try to bridge the gap with one of the options described on the right. If you have not had any health care plan for over 62 days prior to accepting this job, you may be required to wait for 12 months before your MS is covered.

Plan Benefits and Your Costs

When reviewing a health-care plan, consider the following:

- **Coverage for MS.** Make sure the health-care plan will cover MS treatment and therapies.
- **Type of plan.** Some employers give you a choice between different types of health-care plans. Read about each type, and choose the plan that is best for a chronic condition as well as the routine medical needs of you and your family. Ask yourself questions such as, “Can I still go to my current doctor/hospital? Am I satisfied with my choice of doctors and hospitals? Will I be able to get care from specialists when I need it?”

- **Costs.** If you are deciding between health-care plans, compare the costs of co-pays, prescription drugs, your share of the premiums, and so on with the overall benefits offered by the plan. Keep in mind that an inexpensive health-care plan may not be the least expensive in the long run.

Options for Bridging the Gap Between Health-Care Plans

If you are switching jobs and will have to wait to join a new health-care plan, consider using COBRA or another option to bridge this gap.

COBRA

The Consolidated Omnibus Budget Reconciliation Act of 1985 (referred to as COBRA) allows you to keep your previous employer's health-care plan for 18, 29, or 36 months, depending on the circumstances, if a “qualifying” event occurs. This federal law applies to employers with 20 or more employees.

Qualifying events for employees include the following:

- Your employment ends (voluntarily or involuntarily) for reasons other than gross misconduct.
- Your work hours are reduced to the point you no longer qualify for your employer's health-care plan.



COBRA is helpful, but there is a catch. You must pay the full cost of coverage, at the employer's group rate, plus up to 2 percent to cover administrative fees. If that cost seems steep, keep in mind how much more expensive it would be to pay for MS treatment *without* a health-care plan or with a costly individual plan. Most important, keeping your insurance coverage in force enables you to avoid any pre-existing conditions waiting period under the new employer's plan as long as you met waiting-period requirements under prior coverage.

Other Options

If you are not eligible for COBRA or your coverage under COBRA runs out, consider these options:

- Find out if you can convert your company's group policy to the insurance company's plan for individuals. You will

pay more for fewer benefits, but it may be difficult to get an individual policy any other way. Make sure the converted policy covers MS.

- If you are married and your spouse works, find out if you can join your spouse's health-care plan. If this happens because of your change in employment status, you will not be considered a late enrollee.
- Talk with an insurance agent about a temporary health-care plan. These plans exclude pre-existing conditions, but at least you would be covered for other health-care costs.
- Find out if your state has an insurance program for hard-to-insure individuals. Contact your state's insurance regulatory agency.

Other Useful Job Benefits

Although health-care coverage is the most important employer-paid benefit, two other valuable benefits to look for are disability insurance and life insurance.

Keep in mind that employer-sponsored disability plans may exclude pre-existing conditions that could lead to a future disability, so a new employer's plan may or may not cover you some period of time, because of your MS.



Some employers also provide a certain amount of life insurance as an employee benefit. That amount may be sufficient for your needs, or you may want more coverage. Because of MS, it is unlikely that you can buy individual life insurance at standard rates. However, your employer's plan may allow you to buy additional group life insurance above the amount the company provides.

Considering Self-Employment

Many people with MS are successfully self-employed. In fact, it may be easier to rest or attend doctor appointments when you are self-employed than when you work for an employer.

Before quitting a job and taking this path, however, ask yourself some serious questions, such as:

- What will happen to my health-care coverage, and how much will it cost to get coverage on my own?
- What other forms of insurance does my employer provide that I will have to do without or secure on my own?

- Do I have the energy and stamina to start my own business?
- Can I live without a steady paycheck?
- Can I afford to maintain and update the business equipment I will need?
- Do I have the money necessary to start a business?
- Do I have a wide network of professionals who can make referrals to my business?

The Small Business Administration (SBA) recommends having enough money set aside to pay for operating expenses for at least one year. Operating expenses include whatever salary you intend to pay yourself, loan payments, and other costs, such as equipment costs or health-care premiums.

The SBA offers business counseling, training, and information services, including the Service Corps of Retired Executives, Business Information Centers, Small Business Development Centers, and Women's Business Centers. For more information, visit the SBA Web site at www.sba.gov or call the Small Business Administration Answer Desk at 1-800-UASK-SBA (1-800-827-5722).

The Job Accommodation Network (JAN) also provides valuable tips and information for the would-be business owner. Visit its Web site at www.jan.wvu.edu and click the Small Business and Self-Employment Service tab.

My Plan for Finding a New Job

1. I will use the following resources to look for a job: _____

2. I will tell potential employers the following information, if any, about my MS: _____

3. I will keep health-care coverage between jobs by doing the following: _____

4. I will explore self-employment possibilities by doing the following: _____

“It took me a long time to accept help. I’ve always been proud of my independence. But the day came when I had to admit that MS is a tough disease and I couldn’t fight it alone.”

—Carol, diagnosed in 1963

Life Without a Health-Care Plan

If you do not already have a health-care plan, it may be difficult to buy private coverage after being diagnosed with MS. However, most states guarantee access to state sponsored health-insurance coverage regardless of a pre-existing condition.

These state-sponsored plans, commonly referred to as “high-risk pools,” are designed to provide health-care coverage for individuals who have been turned down by private plans. Check with your state’s insurance regulatory agency. The cost of a state plan may be high, but at least you will have health-care coverage.

Hiring Home Help

There may be times when your MS symptoms make it difficult to take care of your home or yourself. If you decide to hire help, the following tips may be useful:

- Before hiring anyone, identify your needs. For example, do you need someone to provide medical services, personal care, homemaking, or companionship? This will determine whether you need a nurse, a health aide, a housekeeper, or a friend.





- To help determine what kind of assistance you may need, use the “Help at Home: Needs Assessment” worksheet on page 37, which is adapted from the NMSS publication, *Hiring Help at Home: The Basic Facts*. Another useful publication is PVA’s *Managing Personal Assistants: A Consumer Guide*.
- Find out if your insurance or a program such as Medicaid, Medicare, or VA covers the service. (See Chapter 4 for more information about Medicaid and Medicare.) Your state’s vocational rehabilitation agency might know about programs to help pay for a personal assistant, especially if you need an assistant in order to work. In some communities, personal assistance services are provided by state or county funds. Also call your local chapter of NMSS or PVA for information and suggestions.
- You can go through an agency or hire someone on your own. To get a list of recommended agencies or individuals, call the social worker at your nearby hospital, nursing home or rehabilitation facility, a local NMSS or PVA chapter, or your doctor. Another source of information about hiring in-home help is the U.S. Administration on Aging’s Eldercare Locator. Call 1-800-677-1116 or go to www.eldercare.gov and click Caregiver Internet Resources.
- If you use an agency, you likely will be relieved of many of the bookkeeping and hiring responsibilities. In addition, if you are receiving Medicare benefits, know that Medicare requires skilled care to be provided by a licensed, certified home health-care agency in order to be covered. However, it typically costs more to go through an agency than to hire someone on your own, and you will not have as much control over duties and scheduling.
- If you are using an agency, find out if the agency works with Medicare, Medicaid, VA, or your insurance company (private insurance may have a home health-care benefit). Also find out if the agency charges a sliding fee depending on the level of services provided and your income.
- If the agency pays the personal assistant directly, you will not be responsible for payroll taxes. However, if you pay the assistant out of your own funds and the amount exceeds \$1,400 a year (for 2003), the assistant is considered your employee, and you must pay state and federal withholding taxes and Social Security taxes. Consult an accountant or other financial advisor to help you set up a system for paying your assistant, keeping necessary records, and filing any required taxes. To learn more, visit the Internal Revenue Service (IRS) Web site at www.irs.gov and search for Publication 907, *Tax Highlights for Persons with Disabilities*, which includes tax information related to household employees.

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- Money is not the only way to pay for services. For example, you might offer English or computer lessons in return for services. Be aware, however, that non-cash compensation may be taxable. Consult your tax advisor.
- If you decide to hire someone on your own, consider conducting interviews away from home to protect your privacy. Ask a family member or friend to come with you to protect your safety and to give you another person's reaction to the applicant. Ask applicants for references and how much they charge.
- Your home-care employee is likely to be a stranger. Do not be too trusting too quickly. Know how much cash you have in the house and where it is kept. Keep your checkbook, credit cards, and other valuables under lock and key.
- If the assistant shops for you, use cash or distribute one check at a time. Never give out your credit card. Always ask for and read the receipts.
- List the duties to be performed in writing so there are no misunderstandings.
- Arrange for periodic, unannounced visits by friends and relatives while your employee is on duty.
- If your caregiver is a family member and you recognize that he or she needs assistance, contact the National Family Caregivers Association at 1-800-896-3650, or go to www.nfcacares.org.

“Before I had MS, I was a jogger. Now I use a cane or walker, and I hire someone to help me at home. I’ve slowed down, but that gives me more time to notice the world around me. I keep telling myself ‘don’t give up, don’t give in.’”

—Beatriz, diagnosed in 1994

Help at Home: Needs Assessment*

Use this worksheet as a tool to help you and your family identify your needs and how they will be met. Be very specific regarding

medical needs, because a trained person must help you with some of them. Revisit this worksheet as your needs change.

Needs

Who Will Help?

	Self	Family Member	Friend (Volunteer)	Housekeeper/ Companion (Paid)	Health Aide**	Nurse/Therapist
Housekeeping						
Laundry						
Cleaning						
Meals						
Grocery shopping/ errands						
Bill paying/ record keeping						
Minor repairs/ maintenance						
Companionship						
Reading						
Writing						
Hobbies						
Travel						
Medical						
Medication, administering					See **	
Therapy (physical, occupational)					See **	
Personal Care						
Bathing						
Dressing						
Feeding						
Hair and nails						
Bowel/bladder program						
Exercise						
Transfers						
Transportation						
For self						
For children/others						

* Adapted, in part, from "Help at Home: Needs Assessment" worksheet found in the NMSS publication, *Hiring Help at Home: The Basic Facts*.

** A health aide can provide medical services only under supervision of a nurse.

Independent Living Centers

Nonprofit independent living centers across the country provide a wide range of services and typically are staffed by people with disabilities.

Independent living centers often provide counseling and training in new skills that can help you to live as independently as possible (for example, hiring home help or finding accessible, affordable housing). They also can assist with Social Security appeals or help you assert your rights under the Americans with Disabilities Act.

To find an independent living center, call your state's vocational rehabilitation agency. You also can call the National Council on Independent Living at 1-703-525-3406 or go to www.ncil.org. Click National Directory of Centers for Independent Living and then click on your state.



Adapting Your Home

In addition to thinking through issues dealing with employment and hiring help, you also may need to make some changes to your home.

Deciding if or how to adapt your home will depend on your symptoms. For example, if your symptoms are mild, all you may need to do is get rid of clutter or rearrange furniture so you can easily move around your house. If symptoms are more severe or frequent, ramps, wider doorways, lower countertops, or other changes may be necessary.

Reviewing your MS journal may help you decide what changes are needed now. Also, the NMSS publication, *At Home with MS*, and the PVA book, *Accessible Home Design*, provide useful tips.

Managing Costs

Here are some ideas for managing the costs of home adaptations:

- **Choose a contractor carefully.** Get bids from three licensed contractors, compare prices, and check their references. The contractor may ask for a partial payment to buy materials, but do not pay the final bill until the work is completed to your satisfaction.
- **Find volunteer groups** that may do some of the work for free. Ask your hospital social worker, insurance caseworker, or local NMSS or PVA chapter for suggestions.



- **Check into tax deductions.** The costs to change your home for medical necessity may be deductible from your income when calculating your taxes. Get a doctor's letter to document medical necessity and check with your tax advisor.
- **Contact your state's housing and finance agency.** Ask about eligibility requirements for funds that may be available to assist in retrofitting your home.

Tips for Renters

- **If you decide to move to an apartment,** look for one that has a sidewalk or elevator entrance instead of stairs, wider doorways, bathrooms with grab bars, and appliances and light switches that are easily accessible. Your local housing authority or independent living center can guide you to apartment complexes that have these modifications.

- **If you already live in an apartment unit** that is not adequately accessible, ask your property manager if you can move into a handicapped-accessible unit, or ask the apartment owner to modify your apartment for your disability. (Your state may require that a certain number of units in an apartment complex be accessible to people with disabilities, although these rules usually apply to larger complexes, not to small mom-and-pop rental units.) If landlord modification of the apartment is not possible, ask about ending your lease or research regulations for modifying the apartment at your own expense.
- **If your landlord is unwilling to work with you,** contact your local fair-housing agency. For more information about fair housing, visit the Web site of the U.S. Department of Housing and Urban Development at www.hud.gov. Click About HUD at left, and then Fair Housing/Equal Opportunity at right.

“As luck would have it, my house has a lot of stairs. I didn’t want to sell my home, so I started to think of the stairs as a painful exercise program. My family reinforced the railings so I could really depend on them to support me. I go down them slowly, but I think my stairs have helped my mobility.”

—Annie, diagnosed in 1982



Paying for Assistive Devices

You've probably heard the term "assistive devices." Think of them as items that can help you do things more easily, from cooking and walking to reading and working. An assistive device could include a wheelchair or a special computer screen, or it could be a cane or an easy-to-grip door handle.

Having the equipment you require can make the difference between dependence and independence. In many cases, it's a necessity, not a luxury.

Here are some points to keep in mind when looking for help in paying for an assistive device:

- Know your needs. Talk to your doctor or therapist. Become your own best advocate for what you need.
- Private insurance, Medicare, Medicaid, and VA may pay for assistive devices if they are medical necessities. Ask your doctor to write a prescription for these items.

- Call your state's vocational rehabilitation agency. It may provide funding help if the device is needed for work.
- Check out state assistive technology projects. The project in your state may offer low-interest loans, equipment exchanges, or equipment recycling. For more information, call the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) at 1-703-524-6686, or go to www.resna.org. Click Technical Assistance Project and then the link for your state.
- Keep trying. Don't be discouraged if your first request for funding is turned down. Find out why and apply again. Ask someone who is experienced with funding requests to help you apply. Good resources include a rehabilitation therapist, independent living centers, other people with disabilities, and local chapters of NMSS and PVA.

My Plan for Home Help and Home Adaptations

1. I will look for home help in the following places: _____

2. This is how I will pay for home help: _____

3. I need the following adaptations to my home: _____

4. This is how I will pay for these adaptations: _____

