Adapting:

FINANCIAL PLANNING FOR A LIFE WITH MULTIPLE SCLEROSIS
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Multiple sclerosis (MS) is a complex and unpredictable disease that affects approximately 400,000 people in the United States. If you or a loved one has MS, you know there are good and bad days, because MS is not a “one-size-fits-all” condition. You will find your own way of adapting, whether through the right medications, diet and exercise, or coping skills you will learn.

Another part of navigating MS is managing your money and planning wisely for the future. Just as your MS symptoms are not exactly like someone else’s symptoms, your financial situation also is unique. Now more than ever, you will need to take a clear look at your income, assets, debts, benefits, and other resources.

At first glance, getting a good handle on your finances may seem overwhelming. If you give yourself some time and have a little patience, however, you can accomplish this step.

To make the process easier, the National Endowment for Financial Education® (NEFE®), the National Multiple Sclerosis Society (NMSS), and the Paralyzed Veterans of America (PVA) have produced *Adapting: Financial Planning for a Life with Multiple Sclerosis*. The goal of the booklet is to help you meet the financial challenges that can accompany MS, so you can focus on living your life to its fullest.

“When we are no longer able to change a situation, we are challenged to change ourselves.”

—Victor Frankl, psychotherapist, author, and Holocaust survivor
Being diagnosed with multiple sclerosis (MS) is a major event—and you may think you need to make major changes in your life right away. This can be especially true if you are going through a flare-up, or exacerbation, of your MS symptoms.

As difficult as this is, don’t panic. Depending on your symptoms, you may need to do some adapting, but you probably don’t have to make major lifestyle changes immediately. If you have a job, don’t resign. If you own a home with stairs, don’t sell it yet. Instead, try to keep in mind that the majority of people with MS do not become severely disabled.

Getting Organized

Start by devoting some time to exploring, learning, and recording. First, find out as much as you can about MS. Both the National Multiple Sclerosis Society (NMSS) and the Paralyzed Veterans of America (PVA) offer helpful Web sites and useful publications on a variety of MS-related topics. Visit www.nationalmssociety.org, www.pva.org, and check the Resources section at the back of this booklet to get started.

Next, keep track of your MS symptoms. An “MS journal” may be helpful. Document the ups and downs of your disease—what helps and what doesn’t. Then, plan how you will use this information when you talk to your doctor or employer, file an insurance claim, apply for Social Security or other disability benefits, and take other steps to advocate for yourself.

“When I was first diagnosed with MS, I asked ‘Am I going to die?’ The doctor said that, yes, someday I would die—but not from MS. That was more than 25 years ago. Since then, I’ve had my ups and downs, but I’m still around, I still love life, and I’ve always managed to find a way to pay for the things I need.”

—Leslie, diagnosed in 1978
My MS Journal

Record details regularly about your symptoms and treatment to help develop a clearer picture of your MS. This information can provide the basis for a conversation with your doctor, employer, or insurance company. It also can help support your requests for any changes to your environment, medications, or work schedule that may become necessary.

• Are there certain times of the day when I routinely become tired? ______________________

• Does a short nap renew my energy? ______________________

• What exhausts me most—physical or mental activities? ______________________

• How am I reacting to medications? Are there any side effects? ______________________

• Have there been any changes in medications or dosage? ______________________

• What type of exercise seems to work best for me? ______________________

• What activities are difficult for me to perform? ______________________

• What adaptations have helped me perform activities more easily? ______________________

• How well am I moving around inside my home and at work? ______________________

• Am I struggling with depression, sexual problems, or sleep deprivation? ______________________

• Have I experienced muscle stiffness or spasms? ______________________

• How do I react to certain air temperatures or other weather conditions? ______________________

• Have I recently experienced a new symptom? ______________________
“When my mom was diagnosed with MS almost 30 years ago, it was a time when most parents didn’t talk about diseases with their kids. All I knew was that my mom wasn’t like other moms. One day she might go hiking with us; the next day she might spend in bed. Sometimes I worried that I caused her to be sick—and there were times when I resented her for being sick. I think that if I had been told about the MS sooner, I could have understood what was happening, and I could have helped her more.”

—Evan, son of Margaret, diagnosed in 1975

Reaching Out for Help

Fatigue is the most common MS symptom. This is especially cruel given that you probably are juggling more tasks now than ever before. While you may be dealing with neurologists, clinics, insurance forms, and benefits issues, you also may be a parent, spouse, employee, and homeowner.

Try not to let all of these responsibilities overwhelm you. Allow family and friends to help—in fact, they may need to help. This is their way of fighting MS on your behalf. Try to find ways they can take on certain tasks, such as organizing your bills or running errands. Develop a network of friends and loved ones you can call on from time to time. That way, no one person will take on too many tasks.
Locating Important Papers and Telephone Numbers

Important papers include the following:

- Birth certificate
- Checking and savings account information
- Durable power of attorney document
- Employee benefits information
- Insurance policies (life, health, disability, and long-term care)
- Investment account information
- Loans, including credit card statements
- Marriage certificate
- Military records
- Mortgage/deed of trust
- Social Security card
- Tax returns
- Titles (auto, house, etc.)
- Will

Finding these papers can be one of the tasks given to a partner or trusted friend. Ask this person to make copies and put them in labeled file folders that you can get to easily. Reviewing your important papers may help to identify resources and assets that can help you pay for the management of your MS.

In addition, use the worksheet above to list the names and phone numbers of professionals who can help you with financial questions. These professionals may include your accountant, insurance agent, caseworker, financial planner, and lawyer.
My Professional Advisors

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<tr>
<th>Advisor’s Name</th>
<th>Phone Number</th>
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<td>Accountant/tax preparer</td>
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<tr>
<td>Caseworker</td>
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<tr>
<td>Financial planner</td>
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<tr>
<td>Insurance agent</td>
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<tr>
<td>Lawyer</td>
<td></td>
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<tr>
<td>Other</td>
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</table>

“My friends kept asking me how they could help, so I decided to make a list of things that are difficult for me to do and would be expensive if I had to hire someone to do them. Now, I show the list to my friends when they offer their help, and they can choose one or two items from it.”

—Vivian, diagnosed in 2001
Taking a Financial Inventory

Review your MS journal to see if your symptoms may lead to additional expenses. For example, you may need to pay for regular massages to lessen muscle stiffness, or buy an air conditioner to keep your home cool because of sensitivity to heat. The spending plan worksheets, found in Chapter 3, also can help you estimate your monthly income and expenses.

Next, write down an estimated value of everything you own and the dollar amount of your debts. You’ll need this information as you plan for future expenses or apply for any benefits that are based on financial need. As you do this estimate, take into consideration the IRS’s definitions of value (go to www.irs.gov) and consider obtaining a professional appraisal of valuable assets, such as your home, artwork, jewelry, or other collectibles. Your accountant or other financial advisor can guide you.
Using a Health-Expense Spreadsheet

Another step you or a loved one can take is to create a health-expense spreadsheet. The spreadsheet should list items such as:

- Dates of doctor visits, hospital stays, or other treatments
- Charges for medical services, prescriptions, and medical supplies
- Portions of expenses covered by a health-care plan
- Amounts and dates that you paid for health-care services, and any remaining balances
- Dates any deductibles were met, if applicable

Software programs can help you create a spreadsheet—and even do the math for you. If you do not own a computer, you can create a spreadsheet in a notebook or use the one provided on page 13. Remember to keep copies of your supporting paperwork: doctor bills, health insurance statements, canceled checks, and bank statements in labeled file folders.

Realize that mistakes can happen when medical claims are processed. Even though these mistakes usually are unintentional, they can be costly. Check with your health-care plan to see if it will share savings resulting from any errors you find in medical bills. Take careful notes while in the hospital or receiving treatment, and check the bill against your notes.

If you find possible billing errors, first try to resolve them with the doctor’s or hospital’s billing office. Next, get in touch with your health insurance company.

If the matter remains unresolved, contact your state’s consumer protection office or insurance regulatory agency to file a complaint. Look in the blue pages of the phone book. Another source of help, if you are covered by Medicare, is the State Health Insurance Program (SHIP). To find a SHIP in your state, call the Eldercare Locator, a free public service of the U.S. Administration on Aging, at 1-800-677-1116.
Prioritizing Your Bills

Prioritizing Your Bills

MS and its related costs can strain your finances, but it is important to pay your bills on time to maintain a good credit rating. If this is not possible, decide which bills are the most important and pay them first. (For example, it is important to pay your health insurance bill so you do not lose coverage.)

You also can call the people and companies to whom you owe money. Explain your situation and ask if you can have longer to pay. Many companies have options that will give you more time or may have special programs to help you pay your bills.

(For more suggestions about managing debt, see Chapter 3.)

### My Health-Expense Spreadsheet

<table>
<thead>
<tr>
<th>Date of Service/Medical Purchase</th>
<th>Amount/Date Paid by Health-Care Plan</th>
<th>Amount/Date Paid by Me</th>
<th>Date Deductible and/or Co-Insurance Met</th>
<th>Date Out-of-Pocket Limit Reached</th>
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Reviewing Your Health-Care Plan

As soon as possible, review your health-care plan, so you will know what the plan will cover, what is excluded, and what your out-of-pocket expenses may be. Having this information will help you plan for anticipated medical expenses and strengthen an appeal on a claim if you believe it was denied incorrectly.

Health-care plans can be difficult to read and understand, but there are people who can help you. Check the back of your health-care card for phone numbers to call for information about your plan. If your health-care plan is provided through an employer, someone in the employee benefits department may be able to answer your questions.

When reviewing your plan, determine if it is a major-medical plan or a managed-care plan, such as a health maintenance organization (HMO), preferred provider organization (PPO), or point-of-service plan (POS). Pay particular attention to information about co-payments, co-insurance, deductibles, pre-existing condition exclusion periods, lifetime maximums, and prescription drugs. These topics are discussed in the following sections.

Co-Payment

Most managed-care plans require you to pay a small amount, called the co-payment or co-pay, each time you visit a health-care provider within the plan’s network. The amount of the co-pay may change annually. If your plan also has a deductible, the co-pay will not count toward it. Major-medical plans and some major medical-type benefits under managed-care plans do not have a co-pay.

Deductible

A deductible is the amount you must pay each year before a major-medical plan pays any expenses. For example, if your health-care plan has a $500 deductible, you must pay the first $500 of covered medical costs before the plan begins to kick in. (If the treatment is not covered by the plan, the cost for that treatment will not count toward the deductible.) Managed-care plans, such as a PPO, HMO, or POS, may have a deductible if they permit care from out-of-network providers. Review your plan to determine which provisions apply to the provider you want to use.
Co-Insurance

Co-insurance is the portion of a health-care expense that you pay in addition to the deductible (when these provisions are part of your plan). A typical co-insurance provision says that after the deductible is paid, the health-care plan pays 80 percent of covered charges for a treatment. You pay the other 20 percent. The percentage is your co-insurance amount. Plans vary as to the amount they expect you to pay.

Most plans have a “stop-loss,” “breakpoint,” or “out-of-pocket” limit. This is the maximum amount you will have to pay per person, or per family, each year. For example, an insurance company may have a stop-loss of $5,000. After you have paid $5,000 in deductible and co-insurance payments, the insurance company will pay 100 percent of covered expenses for the rest of the year. Check your plan for details.

Covered Expenses

Regardless of the amount charged by a provider, a plan will only cover certain treatments for certain amounts. Make sure you know what your plan considers a “covered expense,” and if your health-care provider will accept the plan’s payment or will bill you for any amounts not covered by the plan.

Pre-Existing Condition Exclusion Period

A pre-existing condition is a medical problem you had before you joined a health-care plan. With a pre-existing condition, you may have to wait a period of time before the plan will cover that medical condition. This length of time could be three months, six months, or one year. As a rule, a group health plan cannot make you wait more than one year unless you did not enroll in the plan when first offered, in which case the waiting period may be as long as 18 months.

Under the Health Insurance Portability and Accountability Act (HIPAA) of 1996, you will not have to meet a pre-existing condition exclusion period under a new plan if:

• You have had medical coverage for 18 months before changing to a new plan,
• You already have met a pre-existing condition exclusion period under a previous plan, and
• You have not been without health-care coverage for more than 62 days in the last 12 months.
“MS is affecting my body, but one thing I can do is calm my mind. For me, meditation is vital. It has added a wonderful dimension to my life—and it doesn’t cost a penny.”
—Marion, diagnosed in 1996

Lifetime Maximums

Health-care plans usually limit how much they will pay for health care through a “lifetime maximum benefit.” When the limit is reached, the health-care plan no longer pays for medical care. There also may be a limit for a single illness, injury, or condition, or an annual limit on certain medical services or equipment.
Prescription Drugs

Drugs for MS can be expensive. For example, the major drugs approved by the Food and Drug Administration (FDA) for relapsing-remitting MS can cost between $10,000 and $14,000 a year. Plus, you likely will require other medications to manage the disease and its side effects. Even if your health-care plan offers prescription drug coverage, you may have to pay part of the cost of these medications, so it’s important to plan for this expense.

Start by finding out whether the medications you need are covered by your health-care plan. This information is available in the plan’s “formulary,” which is a list of drugs the plan will cover. Many health-care plans cover some or all of the drugs that have been shown to modify or slow the course of MS.

If you are having difficulty paying for your medications, consider the following options:

- The companies that manufacture the major disease-modifying drugs may offer prescription drug assistance programs. Each program has its own qualifications. Begin by reading Comparing the Disease-Modifying Drugs, published by NMSS.
- Information about other prescription drug assistance programs for people with limited resources can be found on Medicare’s Web site at www.medicare.gov, or go to www.phrma.org. Several states also have prescription drug assistance programs.
- Talk to your doctor about prescribing a less expensive drug or helping you apply for a prescription drug assistance program.
- Shop for the best price—and the best pharmacy. Compare local prices with mail order or online pharmacies, including delivery charges. If you decide to use a mail order or online pharmacy, choose one that requires a written prescription from your doctor. Be careful about using foreign pharmacies, because of the importance of ensuring that the product you order is genuine, of the right strength, and uncontaminated.
- Order a copy of Free and Low Cost Prescription Drugs. This 48-page booklet from the nonprofit Cost Containment Research Institute lists nearly 1,200 brand-name drugs available from drug companies at a large discount for those who qualify. The booklet costs about $5. For ordering information, visit the Institute’s Web site at www.institutedc.org.
- If you are a veteran, you may qualify for Department of Veterans Affairs (VA) health benefits, which include prescription drugs. You must enroll to receive benefits. For more information, see page 18.
Applying for VA Benefits

If you are a veteran discharged from active military service under other than dishonorable conditions, you may qualify for medical care and services from the Department of Veterans Affairs (VA). Even if you have other health-care coverage, apply for VA benefits if you are a veteran to allow the VA to determine your eligibility. That way, if one program does not cover all of your health-care expenses, you may be able to get coverage from another.

The VA health-care system is run by the Veterans Health Administration, which works through a network of hospitals, clinics, nursing homes, and readjustment counseling centers known as vet centers.

To enroll in the VA health-care system, you must complete VA form 10-10EZ. You can obtain the form by visiting, calling, or writing any VA health-care facility or veterans benefits office. You also can order the form by calling 1-877-222-VETS (1-877-222-8387) or visiting www.va.gov/vaforms. For general information about VA health benefits, visit www.va.gov and click Health.

When you apply, VA first will verify that you are eligible. Next you will be assigned a priority number (from 1 to 8; 1 is the highest-priority group). Several factors—such as degree of disability, whether the disability was service-related, whether you are eligible for Medicaid, and so on—are used to determine your priority group number.

Tip: Contact PVA or another veterans service organization for assistance in applying for VA benefits. These organizations can help you make your case for eligibility, which can be especially important if your MS symptoms did not appear until several years after termination of active military service.
Also keep in mind that if your MS progresses, you may be entitled to additional benefits. If you feel that VA has not assigned you the correct priority number or has incorrectly denied you benefits, appeal the decision. Again, PVA or another veterans service organization can help you with the appeals process.
“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
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 WorkTemporarily

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.
CHAPTER 2

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 wwwadata.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.

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**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](http://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.
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](http://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](http://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: ______________________
   ________________________________________________________________________________
   ________________________________________________________________________________
   ________________________________________________________________________________
   ________________________________________________________________________________
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.
• 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.

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


** A health aide can provide medical services only under supervision of a nurse.
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](http://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
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](http://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: ____________________________________________
   ________________________________________________________________________________
   ________________________________________________________________________________
   ________________________________________________________________________________
   ________________________________________________________________________________
Taking control of your finances means:

- Knowing what you have and what you owe
- Making changes as necessary
- Making good choices with the money you spend and save

Developing a Spending Plan

The best way to know how much money you need to live on every month is to make a spending plan. Consider making several copies of the following worksheets so you can use them throughout the year—or whenever your financial situation changes.

“I find myself talking in terms of ‘our’ MS. Only my husband was diagnosed, but believe me, MS affects both people in a marriage. I want him to know that no matter where MS takes us, we’re in this together and we’ll manage the costs together.”

—Sara, wife of Wade, diagnosed in 1985
Step 1: Identify Your Income

Estimate your monthly income.

<table>
<thead>
<tr>
<th>Monthly Income Worksheet</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sources</strong></td>
<td><strong>Per Month</strong></td>
</tr>
<tr>
<td>After-tax wages</td>
<td>$</td>
</tr>
<tr>
<td>Tips or bonuses</td>
<td>$</td>
</tr>
<tr>
<td>Child support</td>
<td>$</td>
</tr>
<tr>
<td>Alimony/maintenance payment(s)</td>
<td>$</td>
</tr>
<tr>
<td>Unemployment compensation</td>
<td>$</td>
</tr>
<tr>
<td>Social Security or Supplemental Security Income</td>
<td>$</td>
</tr>
<tr>
<td>Retirement plan(s)</td>
<td>$</td>
</tr>
<tr>
<td>Private disability insurance payments</td>
<td>$</td>
</tr>
<tr>
<td>VA benefits</td>
<td>$</td>
</tr>
<tr>
<td>Public assistance</td>
<td>$</td>
</tr>
<tr>
<td>Food stamps</td>
<td>$</td>
</tr>
<tr>
<td>Interest/investment income</td>
<td>$</td>
</tr>
<tr>
<td>Other</td>
<td>$</td>
</tr>
<tr>
<td>Other</td>
<td>$</td>
</tr>
<tr>
<td><strong>Total Income:</strong></td>
<td>$</td>
</tr>
</tbody>
</table>
Step 2: List Expenses

List your monthly expenses. If you have been keeping an MS journal, review it before completing this worksheet. If you have not kept a journal, carefully track all of your expenses for a month or two before trying to accurately list them.

<table>
<thead>
<tr>
<th>Sources</th>
<th>Per Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortgage or rent</td>
<td>$</td>
</tr>
<tr>
<td>Utilities (heat, electricity, and water)</td>
<td>$</td>
</tr>
<tr>
<td>Telephone, cellphone, Internet provider</td>
<td>$</td>
</tr>
<tr>
<td>Groceries</td>
<td>$</td>
</tr>
<tr>
<td>Transportation (bus fare, car payment, gas, repairs)</td>
<td>$</td>
</tr>
<tr>
<td>Insurance (cost per month for car, home, health, and life insurance)</td>
<td>$</td>
</tr>
<tr>
<td>Personal assistance care</td>
<td>$</td>
</tr>
<tr>
<td>Prescription drugs, medical supplies, and equipment</td>
<td>$</td>
</tr>
<tr>
<td>Treatments or therapies (massage, exercise classes, alternative treatments, supplements, etc.)</td>
<td>$</td>
</tr>
<tr>
<td>Doctor/dentist bills</td>
<td>$</td>
</tr>
<tr>
<td>Home adaptations or improvements</td>
<td>$</td>
</tr>
<tr>
<td>Clothing/uniforms</td>
<td>$</td>
</tr>
<tr>
<td>Child care/child support payments</td>
<td>$</td>
</tr>
<tr>
<td>Alimony/maintenance payments</td>
<td>$</td>
</tr>
<tr>
<td>Loan/credit card payments</td>
<td>$</td>
</tr>
<tr>
<td>Entertainment (movies, eating out, etc.)</td>
<td>$</td>
</tr>
<tr>
<td>Miscellaneous (classes, gifts, vacations, pet care, etc.)</td>
<td>$</td>
</tr>
<tr>
<td>Donations</td>
<td>$</td>
</tr>
<tr>
<td>Taxes</td>
<td>$</td>
</tr>
<tr>
<td>Savings/retirement plan contributions*</td>
<td>$</td>
</tr>
<tr>
<td>Other</td>
<td>$</td>
</tr>
<tr>
<td><strong>Total Expenses:</strong></td>
<td>$</td>
</tr>
</tbody>
</table>

* Think of saving money as a regular monthly expense. That way, you will be more likely to save.
Step 3: Compare Income and Expenses

<table>
<thead>
<tr>
<th>Write down your total monthly income (from Step 1).</th>
<th>$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Write down your total monthly expenses (from Step 2).</td>
<td>$</td>
</tr>
<tr>
<td>Subtract expenses from income and list amount here.</td>
<td>$</td>
</tr>
</tbody>
</table>
Step 4: Set Priorities and Make Changes

If your expenses exceed your income, do not get discouraged. Here are some ideas to help get spending under control:

- If you are having trouble paying for your medicine, review the suggestions in Chapter 1.
- Make sure you apply for all available programs for which you may be eligible, including VA benefits, Medicare, Medicaid, food stamps, and state programs for low-income individuals.
- Find a doctor you like and stay with him or her. Frequently changing doctors wastes time and money.
- Ask your doctor to write prescriptions for items you may need, such as a brace, walker, or special bed. A prescription shows medical necessity, which makes it more likely that your insurance will pay for it.
- Sell unnecessary items that clutter your house.
- Put away the credit cards—and only bring them out to pay for emergencies.
- Call your local housing authority or talk to your hospital social worker if you are having trouble paying your rent. Ask about Section 8 programs, in which you pay part of the rent based on your income, and the government pays the rest.
- Take advantage of tax deductions and credits. If you do not make very much money, you may be able to use the Earned Income Tax Credit. This credit will reduce your taxes and may even result in a refund. You can claim this credit on IRS Form 1040.
- If you have a lot of medical expenses, you may be able to deduct them from your income for tax purposes. Keep all of your medical bills, as well as receipts for other expenses related to MS. These could include mileage driving to doctor appointments and the cost of modifying your house. Show this information to your tax preparer when it is time to do your taxes.
- Call the IRS or your local senior citizens’ center to ask about free help in preparing your taxes.
Coping with Debt

Debt can limit your choices about health care, therapies, and even some of the small things that help make living with MS easier. If you have cut back on spending, but still have serious debt, consider the following suggestions:

• If you are in debt to a few businesses and in danger of missing payments, call and ask if you can make smaller payments—at least for a while. Most businesses will be more willing to work with you if you make this call before you miss a payment.

• Organize your debts from the highest interest rate to the lowest. Make at least the minimum payment due on all the debts, but put any extra money toward the debt with the highest interest rate. When that debt is paid off, move the extra payment onto the next debt with the highest interest rate. In time, you will pay off your debts and save by avoiding interest costs.

• If you owe money to many businesses, it may be time for outside help. Nonprofit debt-counseling groups, such as Consumer Credit Counseling Service (CCCS) can help you set up a repayment plan. These groups charge a low fee (or no fee) for their services. Call 1-800-388-2227 or visit the National Foundation for Credit Counseling’s Web site at www.nfcc.org.

Avoid companies that focus only on credit card debt. To get out of debt permanently, you will need a plan that takes into consideration all of your expenses.

• Consider bankruptcy as a last resort. A bankruptcy stays on your credit record for 7 to 10 years, depending on the type of bankruptcy. If you are considering bankruptcy, call a lawyer or legal aid clinic before taking any action.

Looking at Investments

You may have money in a 401(k) or other retirement plan, or have other investments. It is a good idea to periodically review where your money is invested. The challenge is to find the right balance between the financial risk you can tolerate and the need for your money to grow.

If you currently are putting money into an employer-provided retirement plan, try to continue doing so. This is one of the best ways to save for your future—and you get special tax breaks. In addition, employers often match all or part of the money you save in the plan. Put at least enough money into the retirement plan to qualify for matching dollars from your employer.
Hiring a Financial Professional

If you decide to hire a financial planner to review your finances, ask your support group or local chapter of NMSS or PVA to refer you to professionals who have worked with people diagnosed with MS. In addition, the following organizations can provide names of financial planners near you:

- American Institute of Certified Public Accountants, Personal Financial Planning Division, [www.cpapfs.org](http://www.cpapfs.org)
- Financial Planning Association, [www.fpanet.org](http://www.fpanet.org)
- National Association of Personal Financial Advisors, [www.napfa.org](http://www.napfa.org)
- Society of Financial Service Professionals, [www.financialpro.org](http://www.financialpro.org)

Interviewing Financial Professionals

There should be a good fit between you and your financial advisor. Consider interviewing three or four advisors, and ask them some of the following questions:

- What are your credentials and background?
- Have you ever worked with a client who has MS?
- Are you familiar with medical plans, government and private disability benefits, and life insurance?
- Are you familiar with the legal rights of people with a disability like MS?
- How often will you review my finances?
- Do you recommend specific products? How do you decide how my money should be allocated?
- How will you be paid (fee, commission from the sale of financial products, fee plus commission)?
- Have you ever been disciplined by a regulatory group?
- Can you supply references?
Setting Aside Money for Unexpected Expenses

Many financial experts advise putting aside enough money to cover your bills for three to six months. This money can help if you lose your job or face other unexpected costs. Because you are dealing with a chronic disease, try to save enough money to cover six months of expenses.

The money you set aside for unexpected events should be placed in an account that you can get to easily. Consider the following options:

- **Savings account.** Savings accounts are easy to open and offer quick access to your money. While they pay only a small amount of interest, savings accounts at banks, savings and loans, and credit unions are safe investments.

- **Money market account.** You often need $1,000 to $10,000 to open a money market account. You may earn more interest on this type of account than with a savings account, but you may have limited access to it. In addition, depending on where you open a money market account, it may not be insured by the federal government. Be sure to ask.

- **Roth IRA.** Even though IRA stands for Individual Retirement Account, you can use a Roth IRA as a way to set money aside for emergencies. Unlike a regular IRA, you can withdraw the after-tax money you put into a Roth IRA without paying a penalty or taxes. However, generally you cannot withdraw any interest the account earns until age 59-1/2 without paying a penalty. You are not taxed on any of the money you withdraw from a Roth IRA provided that you withdraw the money after age 59-1/2, and the Roth IRA has been in existence for at least five years. However, if you become disabled, and distributions are made because of your disability, you do not have to meet the age 59-1/2 rule for distributions of earnings to be income tax free.

Savings and Government Benefits

If you receive government benefits that are based on financial need, such as Supplemental Security Income or Medicaid, your savings could affect your eligibility for those benefits. However, you may be able to participate in a savings program called Plan for Achieving Self-Support (PASS) and still keep your benefits.

PASS permits you to save money to reach a work goal. For example, you could save money to go to trade school or start a business, and the money you save for those reasons will not reduce your SSI payment.

The Social Security Administration oversees the PASS program and must approve your plan. Work with your state’s vocational rehabilitation agency if you think PASS might apply to you. Or, call the Social Security Administration at 1-800-772-1213 to learn more. You also can find information about PASS on the SSA’s Web site at www.socialsecurity.gov/work. Click “Beneficiaries” and go to “Plans for Achieving Self-Support.”

To learn how saving money may affect VA benefits, call a veterans service organization, such as PVA.
My Plan to Take Control of My Finances

1. This is what I will do to cut back on my spending:
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

2. This is what I will do to manage debt and build good credit:
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

3. I will save $__________ a month by doing the following:
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

4. I will learn more about investing money by doing the following:
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
"I didn’t want to use a walker any more than I wanted to wear glasses in the third grade. Now I just think of it as the price I have to pay to see a movie or go to dinner with friends.”

—Jenna, diagnosed in 1983

**If MS Progresses**

MS is an unpredictable disease. Your symptoms could stabilize for years. However, there is a possibility that the disease will progress. This chapter offers suggestions for adapting financially to your changing condition.

**Leaving Work**

If you no longer can perform your job because of MS, it may be time to leave work. However, it may be better to leave work gradually—just in case your condition changes for the better.

**Taking Advantage of Leave and Flextime**

First, talk to your employer about using your paid sick leave and vacation days. Then, ask if the employer will grant you additional unpaid leave. Explore every option that will allow you to keep your job, while having the time off you need to care for yourself. This could include flextime or working from home.

Under the Americans with Disabilities Act, these options can be considered a form of reasonable accommodation, which was discussed in more detail in Chapter 2. Keep in mind, however, that the leave cannot create an undue burden on your employer, and the employer is not required to give you this leave if another effective accommodation is available.
Using Family and Medical Leave

As detailed in Chapter 2, under the Family and Medical Leave Act (FMLA), you may be able to take up to 12 weeks of unpaid leave a year to care for yourself or an immediate family member because of a serious illness.

If your symptoms improve, you have the assurance of being able to return to your job under the rules of FMLA. In addition, you cannot be taken off your employer’s health-care plan during the leave. This enables you to extend the length of time you are covered under your employer’s health-care plan. Of course, you must continue to pay whatever portion of the health-care premium you were paying prior to the leave.

Exploring Disability Insurance Policies

Disability insurance helps replace part of your income if you become sick or are hurt and unable to work. You may have purchased your own disability insurance policy, or perhaps you are covered at work.

Depending on the plan, you may be entitled to long-term or short-term benefits. Short-term disability insurance covers the costs of a temporary absence from work. If your MS progresses to the point where you can no longer work at your current job, you should tap into any long-term disability insurance that you have.

In general, long-term disability insurance does not start paying benefits until you have been disabled for one to six months. Three months is a common waiting period. However, benefits often are paid over a long period of time, usually ranging from several years to the age of 65.

Benefits vary, but long-term disability insurance policies provided by employers typically pay about 60 to 70 percent of your income. The plan also may have a provision requiring you to apply for Social Security disability benefits. Receiving these benefits could reduce the private plan’s payments.

If you have a disability insurance policy, learn how it works. Look for information on the following:

- **Definition of disability.** How does the policy describe “disabled”? Do you fit the description?
- **Monthly benefit amount.** Benefits vary. If it is an employer plan, it is likely to pay a percentage of your income. Read your benefits book to learn how “income” is determined. If you bought the policy, the benefit will be the amount you chose.
- **Benefit period.** How long will the plan pay a benefit?
- **Waiting period.** How long must you wait before you receive a check?
• **Residual or partial disability.** The policy may allow you to return to work on a part-time basis and not lose your entire benefit. Some policies may require only a loss of income to continue paying some benefits, even if you return to work full time.

• **Coordination of benefits.** If your employer pays for your plan, your disability check may not always be a set percentage of your wages. This can happen when you also are receiving income from Social Security or another program. The amount you receive from those programs may be subtracted from the plan’s benefit amount. If you purchased your own disability policy, however, your benefit amount will not be reduced by what you receive from government programs unless you have a rider attached to your policy that provides additional benefits that stop if and when government benefits begin.

• **Taxes.** If you paid the premium for your disability insurance, the benefit is income tax free. If your employer paid the premium, the benefit is taxable. In some cases, there is a blend of employer-paid premiums and worker-paid premiums. For example, your employer may pay the premiums to cover 40 percent of your wages, but you “buy up” to cover another 20 percent. In this case, your total benefit would equal 60 percent of your income. Of that 60 percent, 40 percent would be taxable and 20 percent would not be taxable.

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**Applying for Government Programs**

In addition to applying for disability benefits from a private disability insurance plan, be sure to apply for disability benefits from the Social Security Administration (SSA) if you believe you might be eligible. SSA has two programs that provide a monthly income: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

To qualify for these programs, you must meet the government’s narrow definition of disability. Also keep in mind that if you retire and start receiving a Social Security retirement benefit, you cannot receive an additional disability benefit from Social Security. Social Security disability benefits are paid to people who are under age 65 and cannot work.

**Social Security Disability Insurance**

SSDI is for people who have worked, paid Federal Insurance Contributions Act (FICA) taxes, and then become disabled. If you earn less than $800 a month (as of 2003) due to your disability, you may be eligible for benefits. (The threshold for individuals who are statutorily blind is $1,330 a month in 2003.)
The benefit amount paid under SSDI depends on the following factors:

- How much you earned
- The number of years you worked
- Your age
- When you became disabled

Note: It is a good idea to check your Social Security records to make certain you get credit for all of the jobs you have worked. To obtain a detailed statement of your employment history, complete Form SSA-7050-F4, Request for Social Security Earnings Information. You can do this online at www.socialsecurity.gov or by calling 1-800-772-1213.

SSA’s Web site also has a calculator to help you estimate your SSDI monthly benefit. You can find the calculator by clicking the Social Security Disability Insurance link at www.socialsecurity.gov/disability. Note that your assets do not affect your benefit amount under SSDI. A percentage of your SSDI benefits may be taxable, however, depending on your other income.

Once benefits are approved, they are paid retroactively to the later of the date of application or the sixth month of disability. If you qualify for SSDI, you also may be eligible for Medicare, the federal government’s health-care program. However, the wait to join Medicare is two years after you are eligible for SSDI benefits. Try to keep some other health insurance in force while you are waiting. For example, use COBRA (discussed in Chapter 2) to keep your health insurance plan from your job, join your spouse’s health-care plan, or talk to an insurance agent about temporary insurance coverage that may be available.

As soon as you reach the age for full Social Security retirement benefits (65 in 2003), you automatically qualify for Medicare.

**Supplemental Security Income**

SSI is for people who are unable to work and have little income and few assets. There are no prior-work requirements.

If you qualify, SSI pays you a monthly income. As of 2003, the maximum monthly amount was $552 for an individual and $829 for a couple. (This amount usually increases each year.) Some states supplement the federal payment. To find out the total dollar amount for your state, call SSA at 1-800-772-1213. SSI benefits are not taxable.
If you qualify for SSI, you usually also qualify for Medicaid, the government health insurance program for low-income individuals. SSA will tell you if you need to apply separately for Medicaid in your state. Also be aware that some states have a medical spend-down provision. With this provision, you may be able to qualify for Medicaid if you can document that when you deduct your out-of-pocket health-care expenses from your income, the income falls below the eligibility limit for Medicaid. To learn more, go to the Web site of the Centers for Medicare & Medicaid Services at www.cms.hhs.gov.

Applying for SSDI, SSI Benefits

When applying for SSDI or SSI, talk with others who successfully have filed for these benefits. People at an MS support group may provide useful tips for filing an application.

One man, whose application was approved on the first round, believed it helped that he provided copies of medical records from all of his doctors and hospitals. When he found the government forms did not allow enough space for complete explanations, he typed his information on the computer in small type, printed out the pages, and then cut and taped the answers on the form.

Here are a few other tips:

- **Know that you must meet the SSA’s definition of disability before you can receive benefits.** According to SSA, you must have a physical or mental condition that keeps you from working. The condition must last for at least 12 months or be expected to result in death. In addition, you must be unable to do any “substantial gainful activity.” This means you cannot work at any job where you would earn at least $800 a month before taxes (as of 2003). The SSA will determine if you meet this definition.

- **Start the process as soon as you think you are eligible for benefits.** It may take several months for SSA to reach a decision on your claim. Start by making an appointment to talk to someone at your local SSA office. Call 1-800-772-1213, or go to the SSA Web site at www.socialsecurity.gov to find the office closest to you. You also can apply for benefits online.

- **Take steps to speed up the process.** When you call SSA to make your appointment, ask for a disability report form. Complete the form and give it to the SSA employee who takes your application. Your doctor also can help by providing you with medical information that clearly describes the impact MS has on your ability to work.
• **Keep copies of everything** you give to the SSA in a file folder. Keep any letters the SSA sends to you. Also write down the names of people you talk to, the date, and what they told you.

• **Ask a friend or family member to go with you when you apply.** The rules for Social Security programs can be confusing, so it’s helpful to have another person along to listen and take notes.

• **Insist that your right to apply for benefits is respected.** Don’t let anyone discourage you from filing. Also, know that the SSA employee who takes your application does not determine your eligibility. The decision is made at another office.

• **Use the appeals process.** If your Social Security application is turned down, you can appeal, and you can hire a lawyer or a legal advocate to help you. Your SSA office can give you a list of legal advocates who either do not charge for their help or who charge a low fee. (Under federal law, the lawyer or legal advocate cannot charge more than 25 percent of the retroactive benefits you may receive from SSA.) It’s worth the time and effort to appeal, because eligibility for Social Security benefits, no matter how small the amount, often makes it easier to qualify for other benefits, including housing, transportation, education, job retraining, and food stamps.

One resource for hiring an attorney is the National Organization of Social Security Claimants’ Representatives at [www.nosscr.org](http://www.nosscr.org).

### Returning to Work

Many people with disabilities want to return to work, and Social Security provides a number of ways in which individuals can test their ability to work again while still receiving benefits. These employment supports provide help over a long period of time to allow you to see if you can, indeed, go back to work and gradually become self-supporting again.

For example, if you are receiving **SSDI benefits**, you have at least nine years to test your ability to work. This includes full cash payments during the first year, a 36-month extended eligibility period, and a five-year period in which SSA can start your cash benefits again without a new application. You may continue to have Medicare coverage during this time or even longer.

If you are receiving **SSI benefits**, SSA will consider that your disability continues until you medically recover, even if you work. If you cannot receive SSI checks because your earnings are too high, eligibility for Medicaid may continue. In many cases, if you lose your job or are unable to continue working, you can begin receiving SSI checks without filing a new application.
“My toughest time was when I was filing for benefits. It took all of my energy. People in my support group really helped me get through the paperwork and the frustration.”

—Kelly, diagnosed in 1979

In addition, the Ticket to Work Program helps people on SSI and SSDI get back to work. The program provides access to employment training, job-placement services, and other support services. The program will be fully implemented nationwide by 2004.

To learn more about SSA’s employment supports, visit its Web site at www.socialsecurity.gov/work or call 1-800-772-1213.

Tapping into Other Sources of Income

Consider as many sources of income as possible to pay for your MS care and other bills. Here are some possibilities:

- **Retirement plan.** You may be able to borrow money from a retirement plan at work. Or, if you are permanently disabled, you can withdraw money from a retirement plan without facing a penalty, but you must pay income tax on the amount withdrawn. Remember, people with MS have a near-normal life expectancy, so be careful about using the funds set aside for retirement.

- **VA benefits.** If you are veteran, make sure you enroll in the VA health-care system. You may receive benefits for your disability beyond those provided by Social Security or private disability insurance. (See Chapter 2.)
• **Life insurance.** Permanent insurance policies have a cash value. Examples are whole life and universal life policies. If you have one of these policies, you may be able to use the cash value to get a loan from the insurance company. You also may be able to take some of the cash value out of the insurance policy. Term life insurance does not have any cash value.

• **Long-term care insurance.** If you have this type of policy, it pays nursing home costs and also may pay the cost to hire someone to help you at home. If you have long-term care insurance, ask your insurance agent to help you apply for benefits. If you do not already have this type of insurance, you will not be able to buy a policy because of MS.

• **Mortgage or credit disability insurance.** This kind of insurance might pay your mortgage or credit card bill if you are disabled.

• **Personal property.** A coin, stamp, or doll collection, as well as other types of personal property, might be worth a great deal of money.

• **Real estate.** If you own a home, consider refinancing the mortgage at a lower interest rate. Or, if you can afford the payments, perhaps you could take out a second mortgage to cover short-term medical costs. If you are 62 years old and own a home, another option is to receive cash from the home's equity using a reverse mortgage. (Equity is the value of your house minus the money you still owe on it.) A reverse mortgage is a loan against your home's equity. The loan does not have to be paid as long as you live in the house, but it can be expensive. Before taking out a reverse mortgage, talk to your accountant or financial planner. Also, the AARP Web site provides helpful information about reverse mortgages at [www.aarp.org](http://www.aarp.org) (click Money and Work).

"A lot of fear goes along with MS. It’s a real struggle to keep a positive attitude, especially when money is tight, but if you don’t, you’ve already lost to the disease."

—Anthony, diagnosed in 1980
Family Considerations

As you tap into resources to pay for your care, keep in mind the needs of your family as well. For example, some government programs, such as Medicare, may cover you, but not your spouse and children. On the other hand, if you qualify for Medicaid due to financial need, your spouse and children also may qualify. Or, if you receive assistance from VA, your family may be eligible for some benefits.

If your family was covered under your plan at work and you don’t return to the job, you can use COBRA to keep the family’s coverage in force for 18, 29, or 36 months, depending on the circumstances. Then, you may need to buy a new policy for your family.

The bottom line: As you plan financially for yourself and your family, take advantage of every benefit that’s available.

“I’ve found that taking care of others keeps me from thinking about MS all day. It’s just too easy to let MS take complete control of your life.”

—Lydia, diagnosed in 1976

Continuing to Care for Yourself and Your Family

Wellness is a concept that does not normally come to mind when we think about MS. We usually think in terms of curable or incurable.

MS belies this concept in many ways. It is indeed incurable at the present time; however, it is a complex condition that yields to many treatments and therapies. Although they are not cures, they can provide you with at least some control over your wellness.

Now more than ever, focus on caring for yourself and your family. Keep the following in mind:

• Continue your medications.

• Talk openly with your doctor about MS-related symptoms, such as depression or sexual problems. Treatments may be available.

• Accomplish what you can—when you can. You may have small bursts of energy. Use some of them just to have fun with your loved ones.

• Find exercise routines that work for you. Look into such options as tai chi, aquatic therapy, yoga, or Pilates. Ask a friend or family member to join you. Exercise builds strength and flexibility—and fights depression.
• Contribute where you can. Many nonprofit groups would appreciate your help, even if it’s only for an hour or two at a time. Volunteering can give you a break from thinking about MS.

• Keep your mind active. Read to your children. Do crossword puzzles. Take a class. Mental activities keep the mind flexible and fight cognitive problems.

• Use mobility devices if they help. Isolation can easily lead to depression. Get out of the house when possible, join family outings, and interact with others.

• Discover coping techniques. Meditation, prayer, or biofeedback can calm the mind and decrease the fear that comes with MS.

• Take advantage of every resource available to you. For example, a wealth of ideas is available from NMSS and PVA, including a PVA publication *Multiple Sclerosis: A Self-Care Guide to Wellness*.

MS is what you have—not who you are. Take the time to discover your true value and worth.

My Plan to Tap into Other Sources of Income

1. My plan for tapping into disability insurance benefits that I have at work or on my own:

______________________________________________________________________________

______________________________________________________________________________


______________________________________________________________________________

______________________________________________________________________________

3. My plan for finding other sources of income and financial assistance:____________________

______________________________________________________________________________
MS is not a fatal disease. However, mortality is a fact for all of us—and loved ones will be left behind. This is why estate planning is a good idea for everyone.

Make it a matter of routine to revisit your life insurance and estate planning needs periodically. Addressing these issues shows that you care about your loved ones’ future.

**Life Insurance**

Life insurance—especially for couples or parents—is important. However, you may wonder how much life insurance is enough. The answer varies, depending on such factors as:

- Are you single or do you have a spouse or partner?
- Does your spouse or partner work, and is he or she self-supporting?
- Do you have any dependent children?
- Do any of your children have special needs, such as learning disabilities or serious health conditions?

- Do you have elderly parents who rely on you for financial support?
- How much money have you set aside in relatively safe investments?

Because of MS, you will not be able to buy life insurance at standard rates. However, your employer may allow you to buy additional life insurance above the amount the company provides. If you change jobs, try to convert your group life insurance policy into an individual policy.

A financial planner or insurance agent can answer your life insurance questions. Other resources about life insurance include:

- Consumer Federation of America, [www.consumerfed.org](http://www.consumerfed.org). Click Finance and then Insurance.
- Insurance Information Institute, [www.iii.org](http://www.iii.org)
Estate Planning Paperwork

Estate planning means having certain paperwork in place, including a will, durable power of attorney, health-care proxy, and other documents. To draw up these documents properly, you may want to work with a lawyer. Your state bar association, legal aid society, or state attorney general’s office can help you find the right person and paperwork to plan your estate. If you use a software package to develop a will, it still is a good idea to have a lawyer review the paperwork.

When hiring a lawyer, interview several before making a decision. Ask if the lawyer has experience in working with people with disabilities and experience in estate planning. Find out what the lawyer charges and what you can do to keep your costs down. The American Bar Association has information on hiring and working with lawyers. Visit www.abanet.org. Click General Public Resources.

If you can’t afford to hire a lawyer, you may qualify for legal aid. Many law schools also offer free or low-cost legal services.

Will

You should have a will, and if you are married, your spouse should have one, too. Your will directs how and to whom your money, property, and other assets should be distributed at your death. You also use a will to nominate a guardian for your minor children. If you die without a will, state law will dictate how your assets are distributed and who will look after your children.

Beneficiaries

For some assets, such as life insurance or retirement plans, you name a beneficiary to receive the asset at your death. Make sure your beneficiary designations are up-to-date and match the wishes you have stated in your will. If there is a conflict, a beneficiary designation will override a will.

Durable Power of Attorney

All adults should have a durable power of attorney. This legal document allows you to name the person who will handle your finances if you are unable to handle them yourself. This could include paying your bills or signing your name on financial transactions on your behalf.
Health-Care Proxy and Living Will

A health-care proxy allows you to name a person who will make decisions about your health care if you are unable to make them yourself. A living will allows you to specify the types of medical treatment you want or do not want if you are unable to communicate these choices. All adults should have a health-care proxy and living will. To learn more about these documents, ask your financial advisor, attorney, or a librarian. You also can do an Internet search by going to your search engine and typing, “advance care directives.”
My Plan for Handling Estate Issues

1. This is my plan for making sure I have adequate life insurance:

______________________________________________________________________________
______________________________________________________________________________

2. I have the following documents in place:

   Will: Yes _____ No _____
   Beneficiary designations: Yes _____ No _____
   Power of attorney: Yes _____ No _____
   Health-care proxy: Yes _____ No _____
   Living will: Yes _____ No _____
   Special-needs trust: Yes _____ No _____

Special-Needs Trust

If you receive an inheritance, it could reduce or stop benefits you may be receiving from Medicaid, SSI, or a VA pension. That is because these benefits are paid based on your financial need. (SSDI and VA compensation benefits are not paid based on financial need and, therefore, are not affected by an inheritance.)

With planning, however, your loved ones may be able to leave you an inheritance that will supplement the government assistance you receive, not replace it. A special-needs trust can be established to provide funds for quality-of-life items—such as therapy, classes, or a computer—that are not covered elsewhere. You also may be able to use your own income to set up a similar type of trust, called an income cap trust, in order to meet Medicaid income limits. Check with your state’s Medicaid agency at www.cms.hhs.gov to learn more.

Setting up a special-needs trust requires careful planning. Work with a lawyer who is knowledgeable about estate planning and the rules governing assistance programs for which you may qualify now or in the future.
This booklet has covered many topics—from assessing your current health-care coverage to estate planning. We hope that you have found the booklet useful and will refer to it often as you adapt to the changes that accompany MS. It is the sincere wish of NMSS, PVA, and NEFE that this booklet will help you access the resources that will allow you to manage MS and live well.

Living life to the fullest is the best way to fight MS.
DISABILITY INFORMATION (GENERAL)

- National Council on Independent Living
  877-525-3400 or 202-207-0334
  www.ncil.org

- National Multiple Sclerosis Society
  800-344-4867
  www.nationalmssociety.org. Click Home >
  Government Affairs & Advocacy > Government
  Programs > Social Security Disability

- Paralyzed Veterans of America (PVA)
  800-555-9140
  www.pva.org

- www.disability.gov

- www.govbenefits.gov
  800-333-4636

- U.S. Department of Veterans Affairs
  800-827-1000
  www.va.gov

EMPLOYMENT

- A Guide for People with Disabilities Seeking
  Employment, published by three federal agencies:
  Equal Employment Opportunity Commission, Social
  Security Administration and U.S. Department of

- Disclosure: The Basic Facts (Fact Sheet)
  National MS Society
  800-344-4867
  www.nationalmssociety.org/brochuresbytitle

- Job Accommodation Network (JAN)
  800-526-7234

- Should I Work? Information for Employees
  (brochure) National MS Society
  800-344-4867
  www.nationalmssociety.org/brochuresbytitle

- U.S. Department of Labor
  Office of Disability Employment Policy
  www.dol.gov. Click A to Z and search for
  employment and job information.

- U.S. Equal Employment Opportunity Commission
  (EEOC)
  800-669-4000
  www.eeoc.gov.

- U.S. Small Business Administration (SBA)
  800-827-5722
  www.sba.gov

- Win-Win Approach to Reasonable
  Accommodations (booklet).
  National MS Society
  800-344-4867
  www.nationalmssociety.org/brochuresbytitle
GOVERNMENT PROGRAMS/DISABILITY LAWS

• **ADA and People with MS (booklet)**
  National MS Society
  800-344-4867
  [www.nationalmssociety.org/brochuresbytitle](http://www.nationalmssociety.org/brochuresbytitle)

• **Americans with Disabilities Act: Your Personal Guide to the Law**, published by the PVA.

• **National Network of ADA Centers**
  800-949-4232
  [www.adata.org](http://www.adata.org)


• **Medicare and Medicaid information**
  800-633-4227
  [www.cms.hhs.gov](http://www.cms.hhs.gov)

• **Medicare Information**
  800-633-4227
  [www.medicare.gov](http://www.medicare.gov)

• **Social Security benefits**
  800-772-1213
  [www.ssa.gov](http://www.ssa.gov)

• **Veterans Administration benefits**
  800-827-1000

• **Veterans Rehabilitation agencies.**
  Look for phone number in blue pages of the phone directory, or go to
  [www.askjan.org](http://www.askjan.org). Click Publications and Resources > Resources/Federal > Federal, State and Local Resources > Vocational Rehabilitation Agencies.
HEALTH CARE COVERAGE

- The Disease-Modifying Drugs (brochure)  
  National MS Society  
  800-344-4867  
  www.nationalmssociety.org/brochuresbytitle

- A Guide To Managed Care, For People with Spinal Cord Injury or Disease (Second Edition), published by PVA.  
  888-860-7244  
  www.pva.org  
  PVA Distribution Center  
  P.O. Box 753, Waldorf, MD 20604-0753

- The Keys to Managed Care: A Guide for People with Physical Disabilities; published by PVA. 888-860-7244  
  www.pva.org  
  PVA Distribution Center  
  P.O. Box 753, Waldorf, MD 20604-0753

- VA Health Benefits for People with MS  
  877-222-8387  
  www.va.gov/ms

HOME HELP

  National MS Society  
  800-344-4867  
  www.nationalmssociety.org/brochuresbytitle

- Managing Personal Assistants:  
  A Consumer Guide, published by PVA.  
  888-860-7244  
  www.pva.org  
  PVA Distribution Center  
  P.O. Box 753, Waldorf, MD 20604-0753.

- National Family Caregivers Association  
  800-896-3650  
  www.nfcacares.org

- Tax Highlights for Persons with Disabilities (IRS Publication 907).  
  800-829-1040  
  www.irs.gov

- Living and Working with Disabilities (IRS Publication 3966).  
  800-829-1040  
  www.irs.gov

  800-677-1116  
  www.eldercare.gov
HOUSING

  888-860-7244
  www.pva.org
  PVA Distribution Center
  P.O. Box 753, Waldorf, MD 20604-0753.

- At Home with MS: Adapting Your Environment, (booklet) National MS Society
  800-344-4867
  www.nationalmssociety.org/brochuresbytitle

- U.S. Department of Housing and Urban Development (HUD)
  202-708-1112
  www.hud.gov

PERSONAL FINANCE

- Alliance for Investor Education
  www.investoreducation.org

- American Institute of Certified Public Accountants
  888-777-7077
  www.aicpa.org

- American Savings Education Council
  202-659-0670
  www.choosetosave.org/asec

- Financial Planning Association
  800-322-4237
  www.fpanet.org

- Investment Company Institute
  202-326-5800
  www.ici.org

- National Association of Personal Financial Advisors
  847-483-5400
  www.napfa.org

- National Endowment for Financial Education
  303-741-6333
  www.nefe.org

- National Foundation for Credit Counseling
  800-388-2227
  www.nfcc.org

- Society of Financial Service Professionals
  610-526-2500
  www.financialpro.org
Adapting: Financial Planning for a Life with Multiple Sclerosis was written and prepared as a public service project by the Denver-based National Endowment for Financial Education® (NEFE®); William L. Anthes, Ph.D., President; Brent A. Neiser, CFP®, Director of Collaborative Programs; and Jeannette Herreria, Project Manager of Collaborative Programs.

NEFE is an independent nonprofit foundation committed to educating Americans about personal finance and empowering them to make positive, sound decisions to reach their financial goals. The National Endowment for Financial Education, NEFE, and the NEFE logo are federally registered service marks of the National Endowment for Financial Education. For more information about NEFE, visit www.nefe.org.

The National Multiple Sclerosis Society (NMSS) supports more MS research and serves more people with MS than any other MS organization in the world. NMSS partners with the health-care community to promote quality care and is the only MS organization in the United States that meets the standards of all major agencies that rate not-for-profit groups. Through NMSS’s 50-state network of chapters, assistance is provided to more than a million people annually. For more information about NMSS, visit www.nationalmssociety.org.

The Paralyzed Veterans of America (PVA), a congressionally chartered veterans service organization, works to improve the quality of life for individuals with spinal cord injury and disease through research, education, and advocacy for health care, civil rights, and opportunities for its members and all Americans with spinal-cord dysfunction. For more information about PVA, visit www.pva.org.

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