



**National
Multiple Sclerosis
Society**

Financial Planning for a Life with Multiple Sclerosis

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Introduction

Multiple sclerosis is a complex and unpredictable disease that affects 2.3 million people worldwide. 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, through the right medications, diet and exercise, and coping skills you will learn.

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

—Victor Frankl, psychotherapist, author, and Holocaust survivor

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 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, you can accomplish this step. 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.

Chapter 1: Where I Am Today

Being diagnosed with 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. However, now is the time to start looking at your finances and get a clear picture of your current financial situation. Maximize whatever benefits you currently have. 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. It is important to understand:

- options in the workplace
- helpful government programs
- employer benefits and insurance coverage
- long-term care options

Getting Organized

Whether you're newly diagnosed, or have had MS for a while, getting organized is key. Find out as much as you can about MS, current benefits, savings, investments and government programs for which you may qualify. The National MS Society and its partners offer helpful resources including publications and online tools on a variety of MS-related topics. Visit nationalmssociety.org and check the resources section at the back of this booklet.

Keep track of your MS symptoms. Document the ups and downs of your disease—what helps and what doesn't. A variety of mobile and tablet apps are available, such as Symple and CareZone, to help you do this. 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.

"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? _____
- Do I experience any relief from cooling aids? _____

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.

“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

Next, write down an estimate 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 definition of value (go to 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. Taking a financial inventory can help you identify assets that may be tapped for future expenses and help you determine whether you qualify for government programs.

Locating Important Papers and Contacts

Locating and reviewing your important papers may help to identify resource and assets that can help you pay for the management of your MS.

Important papers include the following:

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

My Professional Advisors

	Advisor's Name	Phone Number
Accountant/tax preparer		
Caseworker		
Financial planner/investment advisor		
Insurance agent (casualty and life/health)		
Lawyer		
Other		
Other		
Other		

Using a Health-Expense Spreadsheet

This may help with insurance claims, preparing income tax returns, applying for government benefits or applying for pharmaceutical assistance programs. 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 insurance plan
- Amounts and dates that you paid for healthcare 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 the next page. Keep copies of your supporting paperwork: doctor bills, health insurance explanations of benefits, 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. It is a good idea to review your bills and claims against the services you received. Check with your health insurance plan to see if it will share savings resulting from any errors you find in medical bills. 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 or ask who your agent is.

If the matter remains unresolved, contact your state's consumer protection office or insurance regulatory agency to file a complaint. A good source of information and assistance, 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 800-677-1116 or visit eldercare.gov. Another good source for all consumers is the Patient Advocate Foundation. Patient Advocate Foundation case managers serve as liaisons between the patient and their health insurer. Visit patientadvocate.org or call 800-532-5274.

My Health-Expense Spreadsheet

Date of Service/ Medical Purchase	Provider Name	Billed Amount	Insurance approved Amount/Date	Amount/Date Paid by me

Make the Best Use of Health Insurance

No matter whether you have MS or no health problems at all, making sure you are enrolled in a health insurance plan at all times may be the single most important way to avoid debt and assure your ability to get the healthcare services you need. Additionally, as of 2015, anyone without qualified health coverage for three continuous months in a calendar year faces a financial penalty unless they qualify for an [exemption](http://healthcare.gov/health-coverage-exemptions/) (healthcare.gov/health-coverage-exemptions/).

Many changes have been made to health insurance in recent years, including new protections against certain practices by insurers that were especially problematic for people with pre-existing and high-cost conditions like MS. The good news is that insurance companies may no longer refuse to insure someone, or charge them more, due to their health. Lifetime caps on benefits are no longer permissible, so no one needs to worry that they will outlive their health insurance. Children and young adults up to age 26 can stay insured through a parent's health plan, and all new insurance policies must meet national standards for coverage and benefits.

The bad news is that even comprehensive health insurance cannot guarantee full protection against high healthcare costs or medical debt. Health insurance is complicated, and everyone must make complex choices about it at different times in their lives. Many health services and other benefits important to people with MS have limitations, (such as 'x' number of physical therapy visits in a year), and some medications your doctor prescribes may not be covered. Deadlines and other details can have a huge impact on your coverage and costs. For these reasons and more, take full advantage of your coverage in order to minimize your expenses as much as possible.

Use your coverage wisely and avoid costly mistakes by understanding:

- what coverage you are eligible for;
- when and how to enroll to assure you are never without coverage;
- how to verify any benefits, exceptions and limits of your coverage;
- how to get help when needed; and
- what common mistakes to avoid.

These points and others about the types of health insurance most people use at different times in their lives are described below and in the chart on page 17. Understanding these basic facts, and [key terms](http://healthcare.gov/glossary/) (healthcare.gov/glossary/) will go a long way toward helping you predict and plan for the costs of care you and your family will need.

Employer-based group coverage

The majority of working aged people (adults up to age 65), and often their dependent spouses and children, are eligible for group health insurance coverage offered by an employer. Generally (and with some exceptions), large employers of 50 employees or more *must* offer group health insurance benefits to their workers, and smaller employers are encouraged to do so through tax incentives. Under these plans, employers typically pay for most of the premium, and employees contribute a portion through a deduction from their paycheck. Most of the expenses that people with MS usually pay are from annual deductible amounts, copayments or co-insurance for covered benefits, plus the full cost of any uncovered or excluded benefits. Typically, employers or their health plan administrators manage annual open enrollment periods and answer enrollees' questions about group health benefits.

Those offered coverage through an employer can opt to buy insurance through the [Health Insurance Marketplace](https://www.healthcare.gov/) (healthcare.gov/) in their state. However, they are not eligible for subsidies unless their employer's plan falls short of minimum standards for coverage and affordability.

[High-deductible health plans](https://www.healthcare.gov/glossary/high-deductible-health-plan/) (healthcare.gov/glossary/high-deductible-health-plan/), which are plans with a higher annual deductible than a traditional insurance plan, have become increasingly common among employer-based group health plans and individual plans. Usually the monthly premium is lower but you have to pay more yourself (your deductible) before the insurance company starts to pay its share. A high-deductible plan can be combined with a health savings account or a [health reimbursement arrangement](https://www.healthcare.gov/glossary/health-reimbursement-account-HRA/) (healthcare.gov/glossary/health-reimbursement-account-HRA/). This allows you to pay for certain medical expenses with untaxed dollars.

For 2016, the IRS defines a high-deductible health plan as any plan with a deductible of at least \$1,300 for an individual or \$2,600 for a family.

Medicare and Medicare Advantage (MA) plans

Medicare is a federal entitlement program that provides health insurance coverage for the following: people who are at least 65 years old; anyone who has been diagnosed with Amyotrophic Lateral Sclerosis (ALS) or End Stage Renal Disease (ESRD) regardless of age; or, persons who qualify for and have received disability insurance benefits from the Social Security Administration (SSA) for at least 24 months regardless of age.

People who qualify for Medicare face many decisions in arranging their Medicare benefits; get help from reliable sources to plan your transition from employer coverage into Medicare and make other major decisions. Lack of awareness about Medicare rules and deadlines can result in lifetime penalties for late enrollment and other costly mistakes. For example, disabled people under age 65 do not become eligible for Medicare until 29 months after the Social Security Administration certifies them as ‘disabled,’ so the need for an alternate source of health coverage during that time period is critically important. See **Options for Bridging the Gap Between Healthcare Plans** in Chapter 2 for more information. Medicare beneficiaries choose between getting their healthcare through ‘Original Medicare’ which reimburses healthcare providers through a fee-for-service system after services are provided, or by enrolling in a Medicare Advantage plan that encourages the use of healthcare providers in a network in exchange for lower up-front costs to the beneficiary. Medicare Advantage plans must cover the same services, medicines and items guaranteed to Original Medicare enrollees, although limits on benefits and the beneficiary’s portion of costs can vary significantly depending on the plan. Original Medicare includes Part A (hospital and in-patient care), and Part B (doctor and other clinicians’ services, lab fees, and equipment used as an outpatient).

Medicare prescription drug plans (aka Part D plans)

Originally, Medicare did not cover medicines needed for anyone that was not in the hospital. But since the federal law changed in 2006, insurance companies have been able to sell separate insurance policies that offer prescription drug coverage for Medicare beneficiaries that don’t have coverage for medications from any other source. For example, some Medicare beneficiaries have prescription drug coverage from an employer group or retiree plan, the VA or Medicaid. Some Medicare Advantage plans include prescription drug coverage in combination with other covered health services and are known as MAPD plans.

Medicare supplemental (aka Medigap) plans

“Medigap” policies supplement Original Medicare and help cover out-of-pocket costs such as copayments and deductibles to varying degrees, depending on the type of Medigap plan. Depending on the market in their state, Medicare beneficiaries may have a wide range of Medigap plans to choose from during their first six months in Medicare. Later on, insurers in most states can refuse to sell a Medigap policy to people under age 65 with a pre-existing condition, although disabled Medicare beneficiaries cannot be turned down for Medigap coverage once they reach age 65. Insurance

companies can only sell standardized policies identified in most states by letters A, B, C and so on. Generally, plans cost and cover more the higher up in the alphabet.

Individual coverage (aka “non-group” plans)

People under age 65 who are not eligible for an employer’s group plan can buy an individual policy for themselves and/or their dependents. Shopping for an individual policy through the [Health Insurance Marketplace](https://www.healthcare.gov/) (healthcare.gov/) allows you to find out if you qualify for a subsidy as you compare options and apply, and professional, no-cost help is available to help you your research options and enroll. Most people who enroll in a health plan through the Marketplace qualify for subsidies based on their income. These subsidies take the form of a tax credit applied to monthly premiums—and in some cases, people can receive assistance with copays and deductibles as well. The amount of subsidy you may receive is based on your estimated household income for the coming year, and these amounts are verified and reconciled through the IRS every year. It is therefore important that you estimate your income as accurately as possible, so you don’t face the possibility of having to reimburse the government for a higher subsidy than you were eligible for in the long run.

Individual policies are generally one year contracts, and it is strongly recommended that you carefully review your coverage options during the open enrollment period each year to see if there are other options that provide better or less costly options for you. Health insurance benefits and costs can change every year, so simply re-enrolling in the same plan can be a costly mistake.

Through the Marketplace, private insurance companies sell policies with a variety of features and price points, though all the plans offered have to meet minimum standards of covered benefits and costs. The annual open enrollment period for Marketplace coverage starts on November 1st for coverage beginning on January 1st, and ends on January 31st. Only people who qualify for a special enrollment period due to a change in circumstances, such as getting married or having a baby, can enroll in coverage through the Marketplace at any other time of year.

Certain individual health plans are also sold outside of the Marketplace through insurance companies, brokers or agents, although subsidies are never available to those who purchase coverage outside of the Marketplace.

Medicaid

Medicaid provides comprehensive insurance coverage for those with limited household income and is administered by each state. In some states, additional eligibility rules apply. There is no age limit for Medicaid and many people are granted partial Medicaid benefits to cover costs that Medicare or other health insurance plans do not cover, including long-term care at home or a nursing facility. Medicaid is jointly financed by the federal and state governments, and applications and enrollment are processed through the [federal Marketplace](https://www.healthcare.gov) (healthcare.gov) or a state's designated agency. Medicaid eligible individuals pay little to nothing for their covered healthcare costs in most states. When an application for individual or family applies for coverage through the Marketplace at Healthcare.gov at any point during the year, and it is determined that they qualify for Medicaid or CHIP, the relevant state agency will be notified.

Coverage for children

If a parent's insurance plan provides coverage for dependents, children and young adults up to age 26 can usually be added to their coverage during yearly open enrollment periods, or a special enrollment period. For lower-income families, coverage for uninsured children is available through the Children's Health Insurance Program (CHIP) or Medicaid. Each state has its own eligibility rules for CHIP. Medicaid and CHIP have no open enrollment period: families can apply at any time of year to find out if they or their children qualify.

Student health plans

Millions of students now get health insurance by enrolling in plans offered by their colleges or universities. Student health plans offer basic insurance coverage that is meant to be affordable and easy to access, but is generally limited. The plans vary in terms of how comprehensive they are, and in price.

Health benefits for Veterans and other Armed Services members and families

Those who served in the military including naval and air service may qualify for healthcare benefits through the Department of Veterans Affairs (VA). The VA also offers coverage for family members of veterans through certain programs. TRICARE provides coverage for active duty service members and their families, as well as retired service members and their families. Veterans under age 65 who are not enrolled in any VA coverage can still get coverage through the Health Insurance Marketplace.

Special cost-help programs

Many people are unaware of cost-help programs that can significantly lower out-of-pocket costs for those who qualify. Although the application processes mean more paperwork and coordination effort for individuals or their caregivers, many people with MS rely on these programs and have greater peace of mind about their finances as a result. Medicare beneficiaries can learn more about programs specifically for them through their State Health Insurance Program.

- Medicare Savings Programs – These are separate programs for income-eligible beneficiaries that help pay for Medicare premiums, Medicare Part A (hospital insurance) and Medicare Part B (medical insurance) deductibles,
 - coinsurance and copayments. You may qualify for the Qualified Medicare Beneficiary (QMB) Program, Specified Low-Income Medicare Beneficiary (SLMB) Program, Qualifying Individual (QI) Program, or Qualified Disabled and Working Individuals (QDWI) Program even if your income and resources are higher than the state limits.
- Medicare Part D ‘Extra Help’ – If you meet certain income and resource limits, you may qualify for [extra help](https://www.medicare.gov/your-medicare-costs/help-paying-costs/save-on-drug-costs/save-on-drug-costs.html#1320) (medicare.gov/your-medicare-costs/help-paying-costs/save-on-drug-costs/save-on-drug-costs.html#1320) from Medicare to pay the costs of Medicare prescription drug coverage. Income criteria and the amount of help can change every year. Partial subsidies may be available to people who are over the stated income or assets limits; be sure to ask about this when you apply.
- Premium Subsidies, Tax Credits, Cost Help and Marketplace Screenings for Medicaid and CHIP – Anyone can get help finding out what type of insurance they and their loved ones are eligible for, including Medicaid or CHIP, by contacting the Marketplace serving their state. You can also do a quick check to determine your eligibility for a subsidy to help make coverage affordable by answering a few [questions](https://www.healthcare.gov/lower-costs/qualifying-for-lower-costs/) (healthcare.gov/lower-costs/qualifying-for-lower-costs/) at [Healthcare.gov](https://www.healthcare.gov). Anyone found eligible for Medicaid or CHIP can get help enrolling any time of year. Applications can be done at [healthcare.gov](https://www.healthcare.gov), over the phone with the help of a Marketplace Navigator by calling 800-318-2596, with a paper application obtained from the Marketplace, or in person with a Community Assistance Counselor. Visit [healthcare.gov](https://www.healthcare.gov) to find no-cost assistance with Marketplace applications in your area.

- **Pharmaceutical Patient Assistance Programs:** All of the manufacturers of the MS disease-modifying therapies (DMTs) offer programs to help qualified individuals pay for the portion of medication costs their health insurance does not cover.

COVERAGE TYPE	WHO'S ELIGIBLE?	WHEN TO ENROLL?	WHAT'S COVERED?	HELPFUL RESOURCES	COSTLY AND COMMON ERRORS
Employer or union-based Group Coverage	Employees or union members (and sometimes their dependents), as determined by the employer or union.	Initial and annual enrollment period, and Special Enrollment Periods under certain circumstances	Plans must provide comprehensive benefits meeting federal standards, though limited quantities and variations in Rx and other benefits are typical.	Plan administrator or employer; Written plan materials provided by the insurer; Customer Service (see phone # on back of member card); the National MS Society- 1-800-344-4867	Missing enrollment deadlines; using an out-of-network doctor, hospital or pharmacy; not checking to make sure a med, service or device is covered;
Individual policy (aka "non-group)	Anyone under age 65 who is not eligible for employer or union group coverage	Initial and annual enrollment period and Special Enrollment Periods under certain circumstances.	Plans must provide comprehensive benefits meeting federal standards, though limited quantities and variations in Rx and other benefits are typical.	Federal or State Marketplace (healthcare.gov)- written plan materials provided by the insurer; Customer Service (see phone # on back of member card); the National MS Society- 1-800-344-4867	Missing enrollment deadlines; using an out-of-network doctor, hospital or pharmacy; assuming that every med, service or device that's prescribed will be covered;

COVERAGE TYPE	WHO'S ELIGIBLE?	WHEN TO ENROLL?	WHAT'S COVERED?	HELPFUL RESOURCES	COSTLY AND COMMON ERRORS
Medicare and Medicare Advantage	People entitled to Medicare must fall into one of three categories: Be at least aged 65; Have been receiving disability income payments from the Social Security Administration for at least two years; or Have a diagnosis of ALS or end stage renal disease (ESRD)	Initial enrollment period is 7 month period beginning begins 3.5 months before 65 th birthday; disabled persons may enroll as of the 24 th month of disability income payments (SSDI) at any age; or upon definite diagnosis of ALS or ESRD. Annual open enrollment period for those who miss their initial enrollment period is the first 3 months of the calendar year.	Comprehensive preventive, primary and hospital care subject to limits and coverage criteria imposed by 'local carriers' (insurers under contract with Medicare to administer benefits in their region). Long term care is never covered. Rx benefits only included in certain private Medicare Advantage plans.	Medicare.gov - 800-MEDICARE; National MS Society 1-800-344-4867; State Health Insurance Programs or Medicare Rights Center National Helpline	Not knowing about penalties for late enrollment; assuming that Medicare covers every provider, service or device prescribed; assuming that long term care is covered; that care provided overseas is covered; that appealing denials or limits in coverage isn't worthwhile. Not planning for dependents' coverage when employer coverage ends; not taking advantage of Medicare Savings Programs
Medicare Supplemental (aka Medigap)	Medicare beneficiaries that are NOT enrolled in a Medicare Advantage plan and NOT eligible for a Medicare Savings Program	Medicare beneficiaries within the first six months after enrolling in Medicare are eligible for any supplemental plan sold in their state; with severe restrictions in eligibility from month 7 and beyond in most states.	Costs not covered by Medicare generally, with significant differences in coverage by plan.	Medicare.gov 800-MEDICARE; National MS Society 1-800-344-4867; State Health Insurance Programs or Medicare Rights Center National Helpline	Missing enrollment deadlines and/or assuming enrollment available anytime; not taking advantage of Medicare Savings Programs
Medicare Rx Plans	Medicare beneficiaries without Rx coverage from another source	Initial enrollment period, annual enrollment period 10/15 to 12/7		Medicare.gov ; Plan Finder; National MS Society	Not taking advantage of Low Income Subsidy

COVERAGE TYPE	WHO'S ELIGIBLE?	WHEN TO ENROLL?	WHAT'S COVERED?	HELPFUL RESOURCES	COSTLY AND COMMON ERRORS
Children's Health Insurance Program	Children up to age 19 from lower-income households (income levels vary by state)	or directly through the CHIP administrator in your community	Comprehensive benefits meeting federal standards, though limits and variations in Rx and other benefits are typical.	Healthcare.gov ; Insure Kids now 877-543-7669	Parents' lack of awareness of CHIP as an option for their uninsured children.
Medicaid	Anyone up to age 65 that meets income criteria; income levels vary by state, and some states have additional eligibility criteria not based on income.	Enroll anytime of the year through Healthcare.gov	Comprehensive benefits, including long term care though varied by state; all benefits subject to limits and exceptions.	Healthcare.gov	Lack of knowledge about eligibility rules, how and when to enroll.

COVERAGE TYPE	WHO'S ELIGIBLE?	WHEN TO ENROLL?	WHAT'S COVERED?	HELPFUL RESOURCES	COSTLY AND COMMON ERRORS
VA Health Benefits; TRICARE	Active duty and retired service members and family of the following: Army, Navy, Marine Corp, Air Force, Coast Guard, Public Health Service, or National Oceanic and Atmospheric Administration, though subject to additional criteria under various circumstances. Eligibility under various circumstances is complicated so it is critically important to explore eligibility carefully	Required enrollment if active duty; others eligible can explore enrollment options and may also have additional coverage from another source.	Preventive care services; ambulatory (outpatient) diagnostic and treatment services; hospital (inpatient) diagnostic and treatment services; Women Veterans' Unique Needs; some may also qualify for long-term care services such as VA Community Living Centers, State Veterans Homes and additional services such as geriatrics and extended care, adult day health care, respite care, home health care, hospice and more	VA.gov/healthbenefits VA Health Benefits 877-222-VETS (8387); Your local VA health care facility's Enrollment Office National Association of County Veteran's Service Officers - http://nacvso.org/ and http://nacvso.org/find-a-service-officer/ to find an officer in your area	Eligibility can be complicated but it can provide affordable option for coverage so important to explore- in many situations, can have these benefits and other health coverage Important to understand coverage and cost sharing; many qualify for coverage with no out-of-pocket costs, but some may have some cost sharing

Important information about your coverage your insurer must provide

Directory of Network Providers: With the exception of Original Medicare, virtually all health insurance plans include financial incentives for their enrollees to use doctors, hospitals, labs, pharmacies and other healthcare providers in their “provider network” (providers that offer services and other benefits to health plan enrollees for a pre-negotiated fee according to a contract). The penalty for using providers out-of-network can be shocking – some plans provide no coverage at all for using out-of-network providers, and others offer limited coverage for them. For that reason, plans that use provider networks are held to increasingly strict standards regarding the amount and type of

providers in their networks, as well as for the accuracy of Provider Directories. If it is necessary for you to maintain access to a certain provider after you change health insurance plans, double check to make sure you know which networks his/she participates in before you switch.

Explanation of Benefits (EOB): As illustrated by [this sample](http://groupbenefits.org/ogb-images/docs/explanation_of_benefits.pdf) (groupbenefits.org/ogb-images/docs/explanation_of_benefits.pdf) and commonly referred to as an EOB form, this is a statement sent by a health insurance company to covered individuals explaining what medical treatments and/or services were paid for following a doctor's visit or other benefit was provided. Review your EOB after you receive treatment because mistakes are common. Check a [glossary](http://healthcare.gov/glossary/) (healthcare.gov/glossary/) to make sure you understand the terminology on the form, and follow-up promptly with the provider or health plan with questions.

Formulary: This is a list of prescription medications your health insurance will cover, and reviewing a plan's formulary BEFORE you enroll in coverage can be very helpful for people relying on high-cost medications, such as MS disease-modifying therapies. Don't be surprised if the formulary excludes certain medications, and understand that the amount of coverage can vary depending on the plan. Formulary lists are often provided on a health plans' website or offered with the Summary of Benefits, and enrollees can always call the Customer Service number to verify that a medication is covered by their plan, or if there are any limits in coverage.

Summary of Benefits and Coverage: New enrollees to a health plan are usually sent a package of materials explaining how the plan works, a member ID card, plus their rights and responsibilities as plan enrollees or members. Note that these descriptions are general. The most detailed list of covered benefits is known as the Evidence of Coverage, and typically provided to the employer or group sponsoring the health insurance plan, but not every enrollee. The Affordable Care Act requires all group and new individual health plans to offer a standardized [Summary of Benefits & Coverage](http://dol.gov/ebsa/pdf/correctedsbctemplate2.pdf) and [Uniform Glossary](http://dol.gov/ebsa/pdf/correctedsbctemplate2.pdf) (dol.gov/ebsa/pdf/correctedsbctemplate2.pdf) to prospective, new and re-enrolling plan enrollees.

Explanation of your rights to appeal health plan decisions: Sometimes, health plans refuse to cover a treatment, service or item for various reasons. All health insurance plans must provide individuals with the right to appeal denials or limitations in coverage, as well as information about how to file an appeal. These explanations may be in the plan materials you received when you first enrolled, and there may be information about the process on the plan's website. You can appeal your insurance company's decision through an "[internal appeal](http://healthcare.gov/how-do-i-appeal-a-health-insurance-companys-decision/internal-appeals/) (healthcare.gov/how-do-i-appeal-a-health-insurance-companys-decision/internal-appeals/)" in which you ask your insurance company to do a

full and fair review of its decision. If your insurance company still denies payment or coverage, the law permits you to have an independent third party decide whether to uphold or overturn the plan's decision. This final process is often referred to as an "[external review](http://healthcare.gov/how-do-i-appeal-a-health-insurance-companys-decision/external-review) (healthcare.gov/how-do-i-appeal-a-health-insurance-companys-decision/external-review)." There are deadlines for filing appeals, and for the insurer to respond to them, and 'expedited appeals' are available if your doctor believes the need for the treatment is urgent.

Prioritizing Your Bills

MS and its related costs can strain your finances, but you must 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, pay your health insurance bill first so you do not lose coverage.

For health insurance related bills we strongly encourage you to attempt to negotiate with the billing party(s). Consumer Reports National Research Center reports that more than 93% of people that try to negotiate their medical debt are successful in getting a lowered cost. Here are some tips for successful negotiation according to the [Patient Advocacy Foundation](http://patientadvocate.org/help.php) (patientadvocate.org/help.php):

- Attend to the bill quickly
- If you have insurance, determine how much was covered under your plan. Check your Explanation of Benefits.
- Remember that the person you are talking to about your request is not the person that sent the bill. Respect, kindness and patience are often reciprocated.
- Inquire about financial assistance (especially if you are working with a major facility).
- Consider negotiating with cash/immediate payment or, if that is not possible, request a payment plan/partial discount. Medical facilities and services must by law negotiate a payment plan with the individual prior to placing in collections which can happen fast if not addressed in the first 30 days.

For more suggestions about managing debt, see Chapter 3.

Chapter 2: Moving Forward After Initial Diagnosis

“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.

What Makes the Difference?

Some people with MS remain productively employed, while others with similar levels of disability do not. According to the National MS Society, 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 including health insurance. Work also provides interaction with other people, a sense of accomplishment and a source of identity and self-esteem.

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. This includes the need for asking for reasonable accommodations.

If you do decide to tell your employer, spend some time explaining your MS symptoms that are impacting you at work. Keep the conversation basic and use non-medical terminology. (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.

Disclosure is a decision that is not to be taken lightly and has the potential of having long-standing consequences, good or bad. Think this through carefully and completely and turn to resources designed to assist in discussing the advantages and disadvantages. Visit nationalmssociety.org/DisclosureDecisions or call the National MS Society at 1-800-344-4867 to discuss. The Job Accommodation Network (JAN) at askjan.org or 800- 526-7234 is also a great resource.

Leaving Work Temporarily

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

Sick leave and vacation

Your employer may allow you a number of days off with pay to recover from an illness. Sick leave is useful, but the time off usually is limited to about 5 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).

* Employers may offer a lump paid time off (PTO) pool to be used for sick days and paid leave.

Family and Medical Leave Act

The Family and Medical Leave Act of 1993 (FMLA) requires employers with 50 or more employees and all public or government employers to provide up to 12 weeks a year to eligible employees coping

with certain family or medical situations. This is unpaid job protected leave. If you take FMLA leave, an employer must restore you to the same or an equivalent position at the expiration of the leave, and the employer must maintain your health insurance benefits during the time you are out.

Employees are eligible to take FMLA leave as long as:

- They have been employed at least 12 months by the employer
- They have worked for at least 1,250 hours (i.e., on average more than twenty-four hours a week) during the preceding 12 months
- There are 50 or more employees of the employer at their work site or within 75 miles of that worksite

An employer must define the 12-month period designated as FMLA leave. Generally, an employer may choose between four different methods:

- The calendar year
- Any fixed 12-month leave year (for example, a fiscal year)
- The 12-month period measured forward from the date any employee's first FMLA leave begins
- A "rolling" 12-month period measured backward from the date of the end of a period the employee intends to use any FMLA leave.

Once the employer has designated a method, however, the same method must be used for all employees. If your employer has not designated the 12-month period in writing and informed employees of it, then you can request the type of leave most favorable to you.

Leave taken under the FMLA can be taken all at once, or on an intermittent or reduced schedule. Although not true for all types of FMLA leave taken, if an employee or an employee's family member's leave is "medically necessary," the employee can take leave on a reduced or intermittent basis without having to seek the employer's permission or approval first. However, 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. Employees may be required to provide medical certification supporting the need for a leave due to a serious health condition affecting the employee or an immediate family member.

Some states offer additional protections that what is available from FMLA. Visit dol.gov/whd/state/fmla/index.htm to determine if your state offers additional protections.

Short-term disability insurance

You may have disability insurance through your employer (group disability insurance) or on your own (individual policy). 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 40-60% of your wages. You must report the benefit as taxable income if the employer paid the premiums for the insurance. Short-term disability often times run concurrently with FMLA.

Understanding the Americans with Disabilities Act

The Americans with Disabilities Act (ADA) of 1990 and the ADA Amendments Act (ADAAA) of 2008 also may protect you from job discrimination and allow you the opportunity to request reasonable accommodations to maintain productivity in the workplace. 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. In addition, under the ADAAA certain conditions, including MS, are presumed to meet the definition of a person with a disability.

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.

A reasonable accommodation is any adjustment or modification to the way a job is done, an employment practice, or a work environment that makes it possible for an employee to perform the essential functions or his or her position. Even if an employee with a disability employee is actually

performing the job, the employer is obligated to reasonably accommodate the employee if he is performing the job with difficulty. The employer does not have to provide the best accommodation available, or even the accommodation specifically requested by the employee, but instead is obligated to provide only an accommodation that is effective for its purpose. Further, an accommodation that is not likely to enable the employee to perform the essential functions of the position is not considered a reasonable one, and therefore not required.

Most employers recognize that wider doorways or lowered desk spaces are reasonable accommodations to assist employees with disabilities in performing the essential functions of their positions. However, some accommodations that are considered reasonable may be surprising. In certain circumstances, employers may be required to reassign job functions to other employees, permit performance of job functions at different locations (such as working from home), or even modify methods of supervision or evaluation. You may be surprised to learn that time off from work, even extended periods of time, can be considered a reasonable accommodation. While your employer is not required to grant you open-ended or indefinite leaves of absence, employers have been required to provide leaves of absence as long as 52 weeks to an employee with a disability.

Logically, your employer is not required to provide an accommodation when it is not aware of, or has no reason to know of the employee's illness or disability. Employees are responsible for informing their employer that an accommodation is needed, unless the disability and the need for an accommodation are known or should be known to the employer. However, if an employee is unable to suggest a reasonable accommodation, the employer is obligated to engage in a dialog with the employee to identify one.

The duty to engage in an interactive dialog is ongoing. Both employers and employees must engage in a good faith interactive discussion to determine whether a reasonable accommodation exists that would permit the employee to perform the essential functions of his job. In some cases, employers may even be required to initiate the discussion if the employee has not done so. Employers are obligated to engage in the interactive process even when it believes the requested accommodation is futile. Employers must take note that refusal to engage in the interactive process is in and of itself a violation of discrimination laws.

Of course, the duty to provide employees with disabilities reasonable accommodations is not without limit. Employers that can successfully show that providing the employee with a reasonable accommodation would pose an undue hardship to the business are not obligated to do so. For example, if an employer can successfully demonstrate that holding an employee's position open

during an extended leave of absence would pose an undue burden to the company, it is not obligated to hold the position open. Considerations specific to each employer, such as the size of the business in proportion to the number of employees, the composition and structure of the employer's workforce, and the nature and costs of the necessary accommodation, will help determine an employer's obligation.

Before requesting an accommodation from your employer, 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. 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 insurance 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 the ADA, 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. JAN is available at askjan.org or 800-526-7234.

The ADA National Network, with regional centers located across the United States, also provides 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 800-949-4232 or go to adata.org.

My Plan for Managing My Job

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

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

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

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. 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 insurance 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.

“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

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 resume.
- Look for a job using the same resources as people who do not have a disability including college career centers, state employment agencies, and websites.
- Check sources that focus specifically on helping people with disabilities find jobs including:
 1. 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. Visit askjan.org for a state-by-state directory. 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.
 2. VA medical facilities or regional offices will know about vocational rehabilitation services available to eligible veterans who need job retraining.

3. There are job boards that allow employers who are actively recruiting qualified people with disabilities and seeking ways to increase diversity in the workplace to post jobs. Look in the resource at the end of this publication for a list of job boards.
- 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 the National MS Society generally recommends that you leave medical information out of a job interview. However, if an accommodation will be necessary, 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. Learn more about disclosure at nationalmssociety.org/DisclosureDecisions.

Job changes and health care

One of the most important job benefits an employer can offer is a health insurance 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 health insurance plan, you may want to look for a new job that has this benefit.

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 insurance portion of the employer's benefits package, pay particular attention to the:

- Waiting period
- Plan benefits and your costs

Waiting period

Before switching to a new employer's health insurance plan, find out when the plan will cover you. There could be a waiting period of up to 90 days—or you could be covered the first day you report to work. Your employer should provide documentation of healthcare benefits including the start date, waiting period (especially if waived) and other important information.

Try to avoid a gap in your medical coverage. If you have to wait to join a new employer's health insurance plan, try to bridge the gap with one of the options described below.

Plan benefits and your costs

When reviewing a health insurance plan, consider the following:

- Coverage for MS care, including the medications and healthcare services you now use. Are your MS specialists in the provider network? If not, are others? Is your drug listed on the formulary?
- Type of plan. Some employers give you a choice between different types of health insurance. 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 insurance plans, compare the costs of copays or co-insurance amounts, 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 insurance plan may not be the least expensive in the long run.

Options for bridging the gap between healthcare plans

The best way to plan for future medical costs is to ensure that you have exhausted all of your options for accessing health insurance. If you are switching jobs and will have to wait to join a new health insurance plan, consider using COBRA, Special Enrollment Period for the Marketplace, coverage through a spouse or partner, 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 insurance 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 insurance plan.

COBRA is helpful, but there is a catch. You must pay the full cost of coverage, at the employer's group rate, plus up to two percent to cover administrative fees. If that cost seems steep, keep in mind how much more expensive it would be to pay for MS treatment without a health insurance plan or with a costly individual plan.

Special enrollment periods for marketplace coverage

Certain life events can trigger a Special Enrollment Period (SEP) including getting married, having a baby, or loss of employer health coverage.

Examples of losing coverage that qualify you for a Special Enrollment Period:

- Losing job-based coverage for any reason:
 - Your employer stops offering coverage
 - You leave your job by choice
 - You get laid off or fired
 - You choose not to re-enroll in a job-based plan when its plan year ends (But see note below.)
(Quitting a plan before the end of the calendar year does not qualify.)
- Your job-based plan not meeting the definition of affordable or minimum value, and as a result you become newly eligible for a premium tax credit
- Losing coverage through a divorce
- COBRA coverage ending. Note: If you cancel COBRA before it ends you don't qualify for a Special Enrollment Period.
- Turning 26 and losing coverage under a parent's plan
- Losing eligibility for Medicaid or the Children's Health Insurance Program (CHIP)(including your child aging off CHIP)

Be careful about dropping coverage.

- If you voluntarily drop coverage before the plan year ends: You don't qualify for a Special Enrollment Period. You also don't qualify if you lose coverage because you don't pay your premium.
- If you don't renew a job-based plan when its plan year ends: You do qualify for a Special Enrollment Period to buy a Marketplace plan. Very important: If the job-based plan you don't renew is

considered affordable and meets minimum value, you won't qualify for a premium tax credit that lowers the cost of your plan. Ask your employer to complete the Employer Coverage tool (PDF) to see if your job-based plan meets these requirements.

Other options

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

- Find out if you can convert your company's group policy to the insurance company's plan for individuals. You will pay more for fewer benefits.
- If you are married and your spouse works, find out if you can join your spouse's health insurance plan. If this happens because of your change in employment status, you will not be considered a late enrollee.

Other useful job benefits

Although health insurance 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 for 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 a traditional employer.

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

- What will happen to my health insurance 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 insurance premiums. Check out the resource section at the end of this publication to learn about how the SBA and JAN can help.

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 insurance coverage between jobs by doing the following:

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

Chapter 3: Taking Control of Your Finances

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.

Step 1: Identify your income – estimate your monthly income

“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

Monthly Income Worksheet	
Sources	Per Month
After-tax wages	\$
Tips or bonuses	\$
Child support	\$
Alimony/maintenance payment(s)	\$
Unemployment compensation	\$
Social Security or Supplemental Security Income	\$
Retirement plan(s)	\$
Private disability insurance payments	\$
VA benefits	\$
Public assistance	\$
Food stamps	\$
Interest/investment income	\$
Other	\$
Other	\$
	\$
	\$
	\$
	\$
Total Income:	\$

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 couple of months before trying to accurately list them. Be mindful of small expenses like coffee, lunches out, impulse purchases that may really add up and become a surprising large line item. Very often cutting back on those can add up to the emergency fund without a feeling of deprivation. The exercise alone of being more aware of spending will naturally result in being more discerning in spending.

As an added bonus, small savings from “brown bagging” or getting movies from the library and not “on demand” can be used toward in more impactful ways.

Monthly Expenses Worksheet	
Sources	Per Month
Mortgage or rent	\$
Utilities (heat, electricity, and water)	\$
Telephone, cellphone, Internet provider	\$
Groceries	\$
Transportation (bus fare, car payment, gas, repairs)	\$
Insurance (cost per month for car, home, health, and life insurance)	\$
Personal assistance care	\$
Prescription drugs, medical supplies, and equipment	\$
Treatments or therapies (massage, exercise class, alternative treatments, supplements, etc.)	\$
Doctor/dentist bills	\$
Home adaptations or improvements	\$
Clothing/uniforms	\$
Child care/child support payments	\$
Alimony/maintenance payments	\$
Loan/credit card payments	\$
Entertainment (movies, eating out, etc.)	\$
Miscellaneous (classes, gifts, vacations, pet care, etc.)	\$
Donations	\$
Taxes	\$

Savings/Retirement contributions	\$
Other	\$
Total Income:	\$

* Think of saving money as a regular monthly expense. That way, you will be more likely to save.

Step 3: Compare income and Expenses

Write down your total monthly income (from Step 1).	\$
Write down your total monthly expenses (from Step 2).	- \$
Subtract expenses from income and list amount here.	\$

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 county's social service/housing agency 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 health care choices and many of the small things that help make living with MS easier. You didn't get into debt overnight and you probably won't get out of it quickly, either. Even if you have a good income now, don't be afraid to admit that you may need professional help – and get it before your situation gets worse.

The first step is to pay yourself first. This idea may sound like a contradiction when you're carrying a lot of debt. However, if you do not have funds of your own to fall back on when your car breaks down or you suddenly need dental work, then you will only go further into debt. Set a target amount for your emergency fund that makes sense given your budget – say, \$500 or \$1,000 to start – and then tuck away what you can, even if it's only throwing your pocket change into a coffee can every night and then depositing the funds into your emergency fund account once a month.

The second step is to prioritize your expenses and debts. Some debts are more important to pay than others. Generally, your spending priorities will be as follows:

1. Essential life expenses, such as food, transportation costs, rent or mortgage and utilities, health insurance and prescriptions. Clothing should not be considered a high priority unless you need to replace key items. Minimize cable TV bills, eating out and other entertainment expenses.
2. Liens and secured debt, such as car loans. Creditors who have a lien against your property can take it, often without going to court first if you are in default.

3. Taxes. If you have taxable income from work, don't have more taxes withheld than you paid last year. Ask your employer to adjust your withholdings if needed so you can use the money to pay other debts. If you owe back taxes, try to negotiate with the tax authorities to see if you can get a payment plan that you can manage. If you make \$52,000 per year or less or are disabled, you may be eligible to get help from a member of the Volunteer Income Tax Assistance (VITA) with your tax issues. For more information about this program, see [irs.gov/Individuals/Free-Tax-Return-Preparation-for-You-by-Volunteers](https://www.irs.gov/Individuals/Free-Tax-Return-Preparation-for-You-by-Volunteers)
4. Court-ordered payments, especially child support and alimony. Failure to make these payments can result in your income and assets being seized or being held in contempt and arrested.
5. Student loans. Federally-subsidized student loans can be consolidated and you can get a payment plan which may allow you lower payments based on your income. You may be able to negotiate a lower monthly payment with a private student loan servicer as well.
6. Unsecured debts, such as credit cards and medical bills.

Next, develop a payment plan for how to manage your debts with the money left over after you've covered the essentials and stick to it. Develop and stick to a pay-off plan, which some financial advisors call a "debt snowball." There are two schools of thought about the best way to do this:

- One approach is to organize your debts from the highest interest rate to the lowest. Make the minimum payment due on all the debts, but put any extra money you may have toward the debt with the highest interest rate. When that debt is paid off, take the money you were paying for the high-interest rate debt and add it to the minimum payment you were pay on the debt with the next-highest interest rate, then do it again. In time, you will pay off your debts and save by avoiding interest costs.
- The other approach is to organize your debts from the least money owed to the most. Pay as much as you can on the smallest debt first and make minimum payments on the rest. When you pay off the smallest debt, take the amount you were paying on that debt and apply it to the minimum payment on the next smallest debt, and so on. You might pay a little more interest this way, but you may see the number of creditors disappear more quickly, which may give you the psychological boost you need to stick with the program.

Whichever method you choose, you need to track your progress (either on paper, with a computer program, or on line), stick with the program, and not run up further debt. Make sure to reward yourself with something inexpensive and fun when you achieve each goal.

If you have steady income and good credit but need to improve your cash flow, you may wish to consider refinancing your home, car or student loans. This option makes the most sense if doing so will make your payments more manageable, if the terms of the new loan are truly fair and reasonable and the interest rate is the same or less than you are paying now, and doing so would allow you to cover other absolutely necessary expenses or to pay off other debts. However, the downside of refinancing is that you will probably pay the loan off over a longer period than if you did not refinance and you may pay more total interest. You can also contact your credit card companies and ask them to reduce your interest rate. Even a one-percent interest rate reduction can help you save money over the long term. Depending on your state's laws and the terms of your separation agreement, if you have lost income due to your illness or have substantially higher medical expenses and owe child support or alimony, the court which granted you your divorce may allow a temporary or permanent adjustment in your order. Make sure to consult with a divorce attorney about this issue. If you are in debt to a few businesses and in danger of missing payments, call and ask if you can make smaller payments for a while. Most businesses will be more willing to work with you if you make this call before you miss a payment and you keep making those payments.

Nonprofit debt-counseling organizations, such as Consumer Credit Counseling Service (CCCS), can help you set up a debt management plan. Call 800-388-2227 or visit the National Foundation for Credit Counseling's at nfcc.org. Under the terms of the plan, you pay the organization a fixed amount on a monthly basis plus a fee for the service. The organization in turn will negotiate lower interest rates with your creditors and make sure the all of the creditors get paid.

If you decide to use this type of service, screen the company carefully to be sure that you avoid companies that focus only on credit card debt. You also need to be careful to avoid scams, as there have been many con artists which will take your money and then never use your money to pay your debts.

Saving and Investing

Pay yourself first

Many financial experts advise putting aside enough money to cover your bills for three to six months to help you survive the loss of a job or face unexpected costs. Because you are dealing with a chronic disease, it is even more important that you cut your expenses and try to save enough money to cover at least six months of expenses if you become unable to work.

While six months of expenses may seem like a lot of money, you can start by creating a “life happens” fund. Save a set amount each week or month as little as you can *before you can spend that money on anything else* until you have \$1,000 to \$2,500 in the bank. This is the money you can use for emergencies, such as car repairs or the dentist, so that you don’t have to use your credit cards to pay for emergencies. Once you’ve hit your target, stop putting money in this account. When you draw down the balance by half, put money back into the account until you’re back at your target balance.

Next, start working on building your reserve account. Take advantage of tools to help you put the money away before you can spend it. This includes automatic transfers out of your checking account or an automatic savings program if offered by your employer. If you do not have this option, use a coffee can and take the money to a bank once a month. Try to save at least six months’ worth of average monthly expenses. (If you are a high wage earner, try to save at least a year’s worth of expenses.) Do not touch this money unless and until you have to. Both the “life happens” fund and the emergency account should be held in a savings or money market account. Most savings accounts allow you to open the account with a small deposit. (Online banks generally offer much better rates than your neighborhood brick and mortar banks and are secured and insured. You can find a list of national on-line savings accounts and their interest rates at bankrate.com)

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.

Investments come in several forms, including individually owned accounts and retirement accounts such as IRAs and employer-provided 401(k) and 403(b) plans. After managing debt and building up an emergency fund, building an investment portfolio is a critical part of saving for potential disability. The challenge is to find the right balance between the financial risk you can tolerate and the need for your money to grow. An experienced, ethical financial advisor can help guide you through your choices (see below).

For many Americans, the core of an investment plan is the retirement plan. Many employers provide a 401(k) or 403(b) plan (for for-profit and not-for-profit employers, respectively). Regular employer-provided accounts take the money out of pre-tax income – in other words, you get a tax break today in exchange for paying taxes on money you withdraw later, when presumably you'd be in a lower tax bracket. However, some employers may also offer *Roth 401(k) or Roth 403(b) accounts*. These accounts let you deposit a portion of your paycheck *after* it has been taxed. You can then eventually withdraw those funds together with income earned tax-free. If the employer offers a matching contribution, not contributing to your account is like leaving free money on the table. In these cases, your contribution is matched up to a specified amount, so your own contribution could be matched up to several thousands of dollars per year. The IRS sets a limit on how much you may contribute to these accounts (\$18,500 in 2016) with additional “catch up contributions” of \$6,000 allowed for persons 50 and over. If you are self-employed, you can have your own retirement plan. Depending on how your business is set up, you could have a SEP-IRA, SIMPLE IRA or self-employed 401(k) plan.

You may also consider opening an *Individual Retirement Account (IRA)*. These accounts allow you to deposit up to \$5,500 per year as of 2016 (plus an additional catch-up contribution of \$1,000 if you are over 50); however, there are limits to what you may deduct if your employer offers a retirement plan at work. Your ability to participate in these accounts depends on your income, and you may not be eligible to use these accounts if you earn more than the IRS allows. These plans are available through brokerages such as Fidelity Investments, Vanguard, or TD Ameritrade, or your personal financial advisor can help you set up an account.

IRAs come in two varieties. The first type is a *traditional IRA*, which is funded with money that you can deduct on your income tax return. Ordinarily, you may begin to withdraw funds from your traditional IRA without penalties for early withdrawal after age 59 ½, and you must withdraw a *minimum required distribution* every year after age 70 ½. However, if you are disabled, you may withdraw the funds earlier than 59 ½ without penalty. The money in the account is taxable when you withdraw it.

The other type of IRA is a *Roth IRA*. *Roth* accounts are funded with money that has already been taxed, so that the money you invest and anything which that money has earned can be withdrawn tax-free. Thus, you can use a Roth IRA as a way to set money aside for emergencies after you've exhausted your emergency funds. There is no minimum age you must achieve to withdraw the money you deposit from the account; however, the account must have been open for at least five years and you must be at least 59 ½ before you can withdraw the earnings. However, there is an important exception to this rule: if you become permanently and totally disabled, you can be younger than 59 ½ to take distributions of earnings tax-free as long as you provide the tax authorities with proof of your disability. Whether you have a traditional or a Roth IRA, you should not take any early withdrawals without first talking to a certified public accountant about what is needed to prove your disability and the impact such withdrawals will have on your taxes.

You may also wish to consider having a stand-alone individual investment account after having sufficient funds in emergency savings. This type of account does not have any restrictions on how much you may invest or when you may buy or sell the investments held, although the company which manages it may require a minimum amount to open the account. Depending on the nature of investments, you may be taxed on capital gains, dividends and interest. A financial professional should guide you about how to best invest your funds in such accounts.

Hiring a financial professional

When hiring a financial professional, begin with the end in mind. Think about what your goal is: Are you looking for investment advice or are you looking to purchase insurance related products? Are you seeking debt solutions or long-term care planning? Most people who seek financial advice have specific questions or concerns they want to address. Any conversation will undoubtedly uncover others as many aspects of financial and legal planning can be interrelated.

There are different types of agents with a variety of certifications. Some charge a fee for advice while others are commission based product sales or investment management fee based. Any financial planner who sells investment products must be registered to do so by your state. You can thus check your state's Secretary of State's and Insurance Division offices to be sure that he or she is licensed to do and that the license is in good standing. Most financial advisers are members of the Financial Industry Regulatory Authority (FINRA), an independent, not-for-profit organization authorized by Congress to protect America's investors by making sure the securities industry operates fairly and honestly. You can check a financial professional's disciplinary history at finra.org/Investors/ToolsCalculators/BrokerCheck. In addition to FINRA, many financial planners

belong to organizations which require significant training in order to become a member and continuing professional education.

If you decide to hire a financial planner to review your finances, contact the National MS Society for a referral to professionals who have worked with people diagnosed with MS. In addition, the following organizations can provide names of financial planners near you:

- Financial Education Partners. The Financial Education Partners (FEP) program was established in 2006 by the Foundation for Financial Service Professionals. It provides pro bono financial planning and education to individuals with special health or financial circumstances. Learn more at nationalmssociety.org/FinancialPlanning.
- American Institute of Certified Public Accountants, Personal Financial Planning Division, cpapfs.org
- Financial Planning Association, fpanet.org
- National Association of Personal Financial Advisors, napfa.org
- Society of Financial Service Professionals, 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?
- What services does your firm provide?
- Have you ever worked with a client who has MS or other chronic diseases?
- Are you familiar with medical plans, government and private disability benefits, and life insurance?
- Are you familiar with the legal issues affecting people with a disability like MS?
- How often will you review my finances? How frequently will you meet with me?
- Is there a minimum amount of money I need to invest with you in order to use your services?
- What is your investment philosophy? How do you measure my investment “success” and what triggers changes to my portfolio?

- What types of financial products do you typically recommend? How do you decide how my investments 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 credits 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 ½ 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 ½, 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 ½ rule for distributions of earnings to be income tax free.

The National Disability Institute offers a financial wellness webinar series for people with MS and other disabilities at realeconomicimpact.org. To learn more about saving, investing, and personal finance, explore some of the publications and resources at the end of this publication.

Savings and government benefits

If you receive government benefits based on financial need, such as Supplemental Security Income or Medicaid, your savings will affect your eligibility for those benefits. Currently, SSI recipients may only own their homes, personal effects, a car, prepaid funeral arrangements and \$2,000 in countable assets (like a bank account). These rules are also true under most Medicaid programs. If you receive Social Security Disability Income (SSDI) or Medicare and do not receive SSI or Medicaid, you may keep any assets you have. If you have state-subsidized health insurance, make sure you take into consideration the program's rules concerning income and assets as part of your financial planning and consult with an elder law attorney about how to best manage your finances and maintain eligibility.

If you are an SSI beneficiary and under age 65, you may be the beneficiary of a self-settled supplemental needs trust, also known as a (d)(4)(A) trust. This trust must be established by a parent, grandparent, guardian, conservator, or by a court order. You cannot be the trustee of this trust, and you cannot have any right to demand that the trustee use the money in a particular manner. If the amount of excess assets are relatively small, you may want to establish a pooled trust account, also known as a (d)(4)(c) trust. These trusts are a collection of small trusts which are managed by a trustee approved by your state's Medicaid program.

If you are on SSI and intend to go back to work or start a business, 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 would not reduce your SSI payment. The SSI money you put into your PASS account will be replaced by Social Security so that you keep your current income.

The Social Security Administration oversees the PASS program and must approve your plan. Work with your state's vocational rehabilitation agency or a Work Incentive Planning and Assistance (WIPA) agency if you think PASS might apply to you. Or, call the Social Security Administration at 800-772-1213 to learn more. You also can find information about PASS at socialsecurity.gov/work. To find your state's vocational rehabilitation agency and WIPA programs, visit choosework.net or call the Ticket to Work program at 866-968-7842.

If you are a veteran, whether your benefits might be affected depends on the type of benefits you are receiving. If you receive disability compensation as a result of being injured while in the military, you cannot be disqualified due to your income and assets. However, if you receive a veteran's pension benefit, your income and assets will be taken into account in determining eligibility. To learn how saving money may affect VA benefits call a veterans service organization such as the 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:

Chapter 4: If My MS Progresses

“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

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, don’t do anything rash and explore all your options. Make sure you have exhausted all accommodations that could help you work effectively. Consider taking time off to see if your MS improves. Determine the impact cutting back on hours would have on disability benefits if you anticipate possibly needing to tap into those benefits down the road, as often times private disability benefits are based on a percentage of your last salary you received from work.

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 flex time 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 insurance 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 insurance 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 short-term or long-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 may consider tapping 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 or normal retirement age.

Benefits vary, but long-term disability insurance policies provided by employers typically pay about 60-70% 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% of your wages, but you "buy up" to cover another 20%. In this case, your total benefit would equal 60% of your income. Of that 60%, 40% would be taxable and 20% would not be taxable.

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.

Navigating through the different government programs available can be complex. An Elder and Special Needs Law attorney can help you with questions about these benefits as part of an overall plan. You can locate an attorney through the National Academy of Elder Law Attorneys, NAELA.org.

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 \$1,170 a month (as of 2017) due to your disability, you may be eligible for benefits. The threshold for individuals who are statutorily blind is \$1,950 a month (as of 2017). Learn more at ssa.gov/oact/cola/sga.html.

The benefit amount paid under SSDI depends on the following factors:

- How much you earned
- 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 at socialsecurity.gov or 800-772-1213.

SSA also offers a calculator to help you estimate your SSDI monthly benefit. You can find the calculator by clicking “Social Security Disability Insurance” at ssa.gov/planners/benefitcalculators.html. 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 healthcare program. However, the wait to join Medicare is 24 months after you are eligible for SSDI benefits. Try to keep some other health insurance in place 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 insurance plan, purchase health insurance through the Marketplace, or talk to an insurance agent about temporary insurance coverage that may be available.

As soon as you reach age 65, you automatically qualify for Medicare if you have paid enough in Medicare taxes during your work life.

Supplemental security income

SSI is for people who meet the Social Security definition of disability and have little income and few assets. There are no prior-work or FICA tax requirements. If you qualify, SSI pays you a monthly income. Some states supplement the federal payment. To find out the total dollar amount for your state, call SSA at 800-772-1213. SSI benefits are not taxable.

If you qualify, SSI pays you a monthly income. As of 2014, the maximum monthly amount was \$721 for an individual and \$1,082 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 800-772-1213. SSI benefits are not taxable.

You may be disabled and work and still receive SSI payments. If your “countable income” exceeds the maximum monthly payment amount noted above, then you would not receive any SSI. All unearned income (interest, dividends, IRA payments, gifts) count against this amount dollar-for-dollar. However, SSI does not count the majority of earned income, and a person with up to approximately \$1,500 per month of earned income (with no unearned income) could receive some SSI payment.

If you qualify for SSI, you usually also qualify for Medicaid, the government health insurance program for low-income individuals. In many states, called “SSI states,” a person who receives at least one dollar of SSI automatically receives Medicaid benefits. 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 healthcare expenses from your income, the income falls below the eligibility limit for Medicaid. To learn more, visit the Centers for Medicare & Medicaid Services at 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 or which requires significant modifications or accommodations for you to be able to work. 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 \$1,170 a month before taxes (as of 2017). 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. Consider making an appointment to talk to someone at your local SSA office. Call 800-772-1213, or go to 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 or to review your materials that are submitted online. The rules for Social Security programs can be confusing, so it's helpful to have another person along to listen and take notes or to make sure you are clear with the impact your MS is having on your ability to work.
- 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, or hire a lawyer or a legal advocate to help you. The [National MS Society](http://nationalmssociety.org) (nationalmssociety.org) and the [National Organization of Social Security Claimants' Representatives](http://www.nosscr.org/) (http://www.nosscr.org/) can give you a list of legal advocates and attorneys. Most work on contingency basis, especially when retained to assist during the appeal process. Under federal law, the lawyer or legal advocate receives payment in the amount of 25%, up to \$6,000, whichever is less, 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.

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. You may have a “trial work period” during which you will receive full Social Security benefits regardless of how much you earn. The trial work period continues until you have worked nine months within a 60-month period. After the trial work period ends, you have 36 months during which you can work and still receive SSDI benefits for any month your earnings are not above the “substantial” level (\$1,170, or \$1,950 if blind as of 2017). After your benefits stop because your earnings are substantial, you have five years during which SSA can start your benefits immediately if you become unable to work because of your condition. 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. You may be able to purchase a medical insurance policy under the Affordable Care Act through your state healthcare marketplace or the federal healthcare marketplace (healthcare.gov). You will be eligible for Medicaid if your income is below 138% of the federal poverty level, and many states allow adults with incomes up to 400% of the federal poverty level to receive Medicaid benefits.

Once you are receiving Society Security benefits, to learn all about the work incentives available to you contact your local Work Incentive Planning and Assistance (WIPA) program. Visit choosework.net or call Social Security’s Ticket to Work program at 866-968-7842.

“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

To learn more about SSA's employment supports call 800-772-1213 or visit [socialsecurity.gov/work](https://www.socialsecurity.gov/work).

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 insurance, 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 healthcare expenses, you may be able to get coverage from another.

The VA healthcare 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 healthcare system, you must complete VA form 10-10EZ. You can obtain the form by visiting, calling, or writing any VA healthcare facility or veteran's benefits office. You also can order the form at 877-222-VETS (877-222-8387) or [va.gov/vaforms](https://www.va.gov/vaforms). For general information about VA health benefits, visit [va.gov](https://www.va.gov) and click Health.

When you apply, the 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 the 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. For example, if your health and care expenses exceed your income, you might be entitled to a Veteran's Pension, a benefit available to veterans in need who served during a qualifying service period, or their surviving spouses. Note: for a VA Pension there is no requirement that disability have been the result of military service. The VA Pension program has qualification criteria in terms of assets and income, but pre-planning with a qualified professional can often help the veteran or surviving spouse qualify for these

benefits, sometimes known as an “Aid and Attendance Pension.” You may wish to seek the guidance of an elder law attorney who has been accredited by the Department of Veterans Affairs. A list of accredited attorneys is available at va.gov/ogc/apps/accreditation/index.asp. You can locate an elder law attorney at NAELA.org. Alternatively, if you have very modest assets, then you may wish to seek the free services available through the Veterans Administration or your local Veterans Service Office often accessible through your local Area Agency on Aging.

In addition, if you have been injured while on active military duty, you may then be entitled to a benefit called Veteran’s Compensation. The value of your non-exempt assets would not affect your eligibility for this benefit. If you feel that VA has not assigned you the correct priority number or has incorrectly denied you benefits, appeal the decision. Again, the PVA or another veterans’ service organization can help you with the appeals process.

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:

- VA benefits. If you are veteran or the widower of a veteran, make sure you enroll in the VA healthcare system. You may receive benefits for your disability beyond those provided by Social Security or private disability insurance. A veteran who sustained a “service connected” injury or disability or aggravation of a pre-existing condition as a result of military service, may be eligible for Disability Compensation from the VA. A veteran (or widow of a veteran) who served at least 90 days of military service and at least one day of active duty during a period of wartime, may be eligible for a VA Pension payment to help pay living expenses if the applicant’s income and assets are below certain limits. If the veteran or widowed spouse is now disabled from some medical condition as determined by the VA, he or she may be eligible for an additional monthly payment called “Aid and Attendance” to help pay the additional costs of care.
- 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 such as an IRA or 401k without facing an early withdrawal penalty, but you must pay income tax on the amount withdrawn. People living with MS have a near-normal life expectancy, so be careful about using the funds set aside for retirement.
- 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 website provides helpful information about reverse mortgages at aarp.org.

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 may also 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.

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 offers 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 non-profit 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. The National MS Society has a variety of resources and publications to help you live your best life with MS.

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:

2. My plan for applying for Social Security benefits:

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

Long Term Care

“It took me a long time to accept help. I’ve always been proud of my independence. But the day came when I had to admit that MS is a tough disease and I couldn’t fight it alone.”- Carol, diagnosed in 1963

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 68.
- Find out if your insurance or a program such as Medicaid, Medicare, or VA covers the service. Do you have long-term care insurance? 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 the National MS Society for referrals.
- You can go through an agency or hire someone on your own. To get a list of recommended agencies or individuals, contact the National MS Society. Another source of information about hiring in-home help is the U.S. Administration on Aging’s Eldercare Locator. Call 800-677-1116 or go to eldercare.gov and search for resources in your area.
- 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 \$1,900 a year (for 2014), 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) at 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 800-896-3650, or go to 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.

Needs

Who Will Help?

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

Revisit this worksheet as your needs change. ** A health aide can provide medical services only under supervision of a nurse.

*Adapted from the National MS Society publication, Hiring Help at Home: The Basic Facts

Adapting Your Home

In addition to thinking through issues dealing with employment and hiring help, you may also 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 counter tops, or other changes may be necessary.

Some adaptations may be possible with the help of assistive devices rather than physical changes to the home. There are a number of websites featuring assistive technologies that are good resources as well as your occupational or physical therapist.

Reviewing your MS journal may help you decide what changes are needed now. Check out the resource section at the end of this publication for a list of brochures available from the National MS Society.

Managing costs

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

- Check 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 the National MS Society 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.
- Tapping into your home’s equity can provide the funds needed to make necessary changes. A mortgage refinance or home equity line of credit can often free up funds to make improvements. In addition, a reverse mortgage can be a useful tool for those over 65 to finance home modifications or to pay for in-home care. However, these should be entered into carefully and treated as a last resort.

Paying for assistive devices

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

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

Here are some tips 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 your state assistive technology projects including the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). The project in your state may offer low-interest loans, equipment exchanges, or equipment recycling. For more information, call 703-524-6686 or visit resna.org and findatnow.org.
- 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 the National MS Society.

Housing

Independent living centers

Non-profit 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 live as independently as possible including 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 can also call the National Council on Independent Living at 703-525-3406 or go to ncil.org.

Non-traditional housing

Adult foster care

The Adult Foster Care model (also referred to as adult family homes or domiciliary care homes) provides residential placement in a private residence where the homeowner receives payment from Medicaid to provide room, board and personal care to persons who are elderly or have disabilities. Adult foster homes provide supervision, oversight and personal care and are licensed by the state. Most states limit the number of individuals who may be served in the setting to five or less. Often these homes are unable to serve individuals who need assistance with administration of medications or who have significant behavioral issues. There are currently eleven states that license adult foster care homes including Arkansas, Arizona, Hawaii, Indiana, Massachusetts, Minnesota, Oregon, Pennsylvania, South Carolina, Washington and Wisconsin. To learn more about these programs in your state, contact your state's Department of Aging.

Group homes

Group Homes provide care within an intimate setting (usually up to four people) with a live-in resident manager. They are privately run and can provide individual or shared rooms. They may provide a variety of services including meals, housekeeping, bathing, dressing, grooming, management of medications and medical needs, and safety supervision. Group homes are licensed, based on the services offered. Medicaid often covers residents who qualify. Some states may not license or inspect

adult foster care homes. Contact your state or county Department of Health for background information/complaints before you select one.

Board and care homes

A Board and Care Home is a housing facility for those who want or need to be in a group living situation and who may need assistance with personal care and daily living activities. Board and Care homes can be a converted single-family home with up to six residents or may be a large building similar to an apartment building with over 100 residents. A characteristic feature of Board and Care is that communal meals are provided, and there is daily contact with staff. If you are considering a Board and Care, licensure should be verified with a county or state licensing office.

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 U.S. Department of Housing and Urban Development at hud.gov.

“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

Subsidized housing

Subsidized housing is provided through public housing owned by housing authorities, the Housing Choice Voucher program and privately owned subsidized housing developments. Usually residents of subsidized housing pay about 30% of their income toward the rent. You will notice in the description of housing programs listed below that an agency called the U.S. Department of Housing and Urban Development (HUD), a cabinet agency of the federal government, is mentioned frequently. It was established for the purpose of providing affordable housing, and overseeing housing, economic and community development. There are a number of HUD programs that have been created to expand affordable, accessible rental units for various populations, including people with disabilities.

Subsidized housing programs include:

- Section 8 Project-Based Housing
- Section 811 Program (supportive housing for people with disabilities)
- Section 202 Program (supportive housing for the elderly)

Eligibility requirements vary. For more information, contact your location housing program and download a copy of the Affordable Accessible Housing Guide from the National MS Society.

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:

Chapter 5: Handling Legal Issues

“It’s been a rocky road at times, but finally I got back to just living my life, focusing on my abilities instead of my ‘disability,’ and thinking about my family’s future.”

—Jeff, diagnosed in 1980

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.

Estate Planning Paperwork

Estate planning means having certain paperwork in place, including a will, durable power of attorney, healthcare proxy, and other documents such as trusts. To draw up these documents properly, you should work with an estate planning attorney. Your state bar association, legal aid society, or state attorney general’s office can help you find the right person to plan your estate.

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 at abanet.org. Click General Public Resources. Members of the National Academy of Elder Law Attorneys, NAELA.org, specialize in the legal needs of people as they age and people with disabilities. NAELA has a free brochure available to consumers, “Questions and Answers When Hiring an Elder and Special Needs Law Attorney.” You can also visit their website for more information on hiring an attorney along with an online directory to find an attorney in your area.

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, or perhaps have a legal clinic available.

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. The will also allows you to

appoint an executor to be in charge of settling your estate. In many states, you may also prepare a memorandum to distribute all tangible property to family and friends, and perhaps attend to a pet.

Beneficiaries

For some assets, such as life insurance, annuities, retirement plans, and IRA's, you name a beneficiary to receive the funds 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. You may also name a contingent beneficiary in the event the primary beneficiary predeceases. Your spouse should also have their beneficiaries checked and possibly name a trust for the benefit of you.

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, signing your name on financial transactions on your behalf, tending to taxes and employee benefits. A successor should also be considered.

Healthcare proxy and living will

A healthcare proxy allows you to name a person who will make decisions about your health-care needs if you are unable to make them yourself. This document 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 or similar document such as advanced directives or living will. To learn more about these documents, ask your attorney. You should also be sure to ask the person you name prior to naming them as they need to be aware of your wishes. Your medical providers and hospitals should be given a copy of this document. You may also wish to consider a Do Not Resuscitate (DNR) form or Physician's Orders for Life Sustaining Treatment (POLST) form regarding health care.

Special-needs trust

If you are receiving certain governmental benefits or an inheritance of other assets, it could reduce or stop benefits that 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 attorney to be sure a trust can assist you. If you anticipate an inheritance from a parent, spouse or anyone else, perhaps they should be leaving funds to a trust for you as opposed to you directly. Upon your demise, these funds can then remain in trust for children, family, charities, etc.

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.

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.

- Can I convert my insurance from term to whole life and do I have a waiver of premium benefit?

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

- Consumer Federation of America, consumerfed.org. Click Finance and then Insurance.

- Insurance Information Institute, iii.org
- National Association of Insurance Commissioners. Call 816-842-3600 or go to naic.org. Click Consumers, then Consumer Publications, and select Life Insurance Buyer's Guide.
- Financial Education Partners- nationalmssociety.org/Resources-Support/FinancialPlanning

Conclusion

There are also many options in planning for one's affairs, and these options should be considered in the process and discussed with your attorney:

- Should I remain single or should I marry?
- Should the marriage be terminated?
- What Social Security and health insurance benefits will I gain or lose based on marital status?
- Are VA benefits available?
- For tax purposes, should I use any retirement plan benefits? (Penalties may be waived if disabled).
- Should I consider having my spouse establish a trust for my benefit to avoid losing benefits?
- Are there options to a trust, such as transfer on death accounts and life estate deeds?
- Do I need a trust to preserve my assets?
- If I have term Life Insurance, can I convert it to permanent insurance?
- If I have permanent insurance, do I have options to purchase additional coverage and do I have a waiver of premium?
- Are all beneficiary designations of Life Insurance, Retirement plans and annuities correctly completed for both myself and my spouse?

- Should I prearrange or prepay any funeral arrangements?
- Should I be filing for disability through work and/or the Social Security Administration?
- Is a Home Equity Loan or Reverse Mortgage appropriate?
- What in-home benefits are available in my community?
- Should I file a joint tax return or separate?
- Should I consider moving my residence to a different state for family, benefits, financial, or health reasons?

My Plan for Handling Legal 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 ____

Durable power of attorney: Yes ____ No ____

Advance Medical Directive: Yes ____ No ____

HIPPA proxy: Yes ____ No ____

Living will: Yes ____ No ____

Special-needs trust: Yes ____ No ____

Additional Resources

Publications

National MS Society

The National MS Society has an extensive library of resources about MS, including publications about treatment options, symptom management and living well with MS. For a list of our publications available for download or by mail, visit nationalMSSociety.org/brochures

The Society's MS Navigators also offer assistance in answering questions about living with MS. These highly skilled professionals can help you connect to resources in your community, access optimal healthcare, meet workplace challenges, understand health insurance, plan for the future and much more. Whether you are a person living with MS, a family member or someone who cares about a person with MS, you can call an MS Navigator at 1-800-344-4867 during business hours Monday through Friday. You can also email us at contactusNMSS@nmss.org or find us on Facebook at [facebook.com/NavigatorMS](https://www.facebook.com/NavigatorMS).

- ADA and People with MS
- At Home with MS: Adapting Your Environment
- Disclosure: The Basic Facts (Fact Sheet)
- Hiring Help at Home: The Basic Facts
- Should I Work? Information for Employees
- The Win-Win Approach to Reasonable Accommodations

Additional publications

- Accessible Affordable Housing Guide
nationalmssociety.org/NationalMSSociety/modifications
- Affordable Care Act Fact Sheet: Key Considerations for Choosing a Health Plan -
nationalmssociety.org/individualinsurance
- Social Security Disability Insurance and Private Disability Insurance Guidebooks -
nationalmssociety.org/SocialSecurityDisabilityInsurance

Paralyzed Veterans of America 888-860-7244 pva.org

- Americans with Disabilities Act: Your Personal Guide to the Law

- The Keys to Managed Care: A Guide for People with Physical Disabilities
- Managing Personal Assistants: A Consumer Guide
- PVA Guide to Federal Health Programs

Veteran's Administration

- Federal Benefits for Veterans, Dependents & Survivors (2014 Online Edition). va.gov/opa/publications/benefits_book.asp
- VA Health Benefits for People with MS. va.gov/opa/publications/benefits_book.asp

IRS 800-829-1040 irs.gov

- Living and Working with Disabilities (IRS Publication 3966) 800-829-1040 irs.gov
- Tax Highlights for Persons with Disabilities (IRS Publication 907)

Online

Information (General)

- benefits.gov
- National Academy of Elder Law Attorneys NAELA naela.org
- National Elder Law Foundation nelf.org/find-a-cela
- National Council on Independent Living 877-525-3400 ncil.org
- National MS Society 1-800-344-4867 nationalmssociety.org
- Paralyzed Veterans of America (PVA) 800-555-9140 pva.org
- US Federal Government disability.gov
- U.S. Department of Veterans Affairs 800-827-1000 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 Justice. ada.gov/workta.htm
- Job Accommodation Network (JAN) 800-526-7234 askjan.org
- National MS Society employment information, 1-800-344-4867 nationalmssociety.org/employment
- National MS Society & Can Do MS Employment Webinar series nationalmssociety.org/telelearning

- SBA 800-UASK-SBA (800-827-5722) sba.gov
- U.S. Department of Labor Office of Disability Employment Policy 866-ODEP-DOL (866-633-7365) dol.gov/odep
- U.S. Equal Employment Opportunity Commission (EEOC) 800-669-4000 eoc.gov

Job boards

- [askearn.org/refdesk/Recruitment/Job Posting](http://askearn.org/refdesk/Recruitment/Job%20Posting)
- careeronestop.org
- usajobs.gov
- indeed.com
- gettinghired.com
- nationalmssociety.jobs

Government Programs/Disability Laws

- Medicare and Medicaid 800-633-4227 cms.hhs.gov
- Medicare 800-633-4227 medicare.gov
- National Network of ADA Centers 800-949-4232 adata.org
- Social Security benefits 800-772-1213 socialsecurity.gov
- Veterans Administration 800-827-1000 va.gov
- Vocational Rehabilitation benefits.va.gov/vocrehab/index.asp
<http://soar.askjan.org/IssueConcern/214>
- U.S. Department of Labor, Family and Medical Leave Act dol.gov/whd/fmla/
- Social Security Ticket to Work, including Work Incentive Planning and Assistance WIPA programs 866-968-7842 choosework.net

Health Care Coverage

- Financial Assistance Programs for medications- www.nationalmssociety.org/DMTassistance
- Healthcare.gov 800-318-2596
- Medicare.gov 800-MEDICARE (800-633-4227)
- Paralyzed Veterans of America PVA.org
- State Health Insurance Assistance Programs shiptacenter.org/
- United States Department of Labor dol.gov/ sample SBC and Uniform Glossary of Terms

Home help

- AARP aarp.org
- Eldercare Locator, a public service of the Administration on Aging, U.S. Department of Health & Human Services 800-677-1116 eldercare.gov
- National Family Caregivers Association 800-896-3650 nfcacares.org
- Rehabilitation Engineering and Assistive Technology Society of North America 703-524-6686 resna.org

Housing

- U.S. Department of Housing and Urban Development (HUD) 202-708-1112 hud.gov
- National Council on Independent Living at 703-525-3406 ncil.org

Personal Finance

- American Institute of Certified Public Accountants 888-777-7077 aicpa.org
- Financial Planning Association 800-322-4237 fpanet.org
- National Association of Personal Financial Advisors 847-483-5400 napfa.org
- National Endowment for Financial Education 303-741-6333 nefe.org
- National Foundation for Credit Counseling 800-388-2227 nfcc.org
- Society of Financial Service Professionals 610-526-2500 financialpro.org

Acknowledgements

Financial Education Partners- Dick Bell, CLU, ChFC, CFP

Silvia Stazio, CFP®

National Academy of Elder Law Attorneys

Hyman G. Darling, J.D

Richard A. Courtney, CELA, CAP

Robert Anderson, CELA, CAP

Sasha Golden

Gene Osofsky

Jennifer VanderVeen, CELA

Paralyzed Veterans of America

National Endowment for Financial Education