

Adapting: Financial Planning for Life with Multiple Sclerosis



Adapting: Financial Planning for a Life with Multiple Sclerosis

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COVER ARTWORK

Katie Gerke

Midmorning Train, Acrylic

Originally from a small town in Northern Alberta, Katie moved to Calgary in 1979 and has called it home ever since. Trained as a Radiology Technician, Katie worked at the General Hospital immediately following graduation. At 24, she decided to travel abroad, and found herself in Saudi Arabia. In addition to her travels to the Middle East, she has also been to Egypt, Kenya and Sri Lanka. After returning home in 1991 she was diagnosed with multiple sclerosis. Today, Katie is a very successful oral painter who has sold her paintings at numerous venues, Church of the Good Shepherd art show, MS fundraisers and through her website.

Katie is an MS Ambassador for the MS Society of Canada, holds several awards including the MS Society of Canada's, President's Award and the 2007 Premier's Gold Award of Excellence. Katie was also named one of Calgary's Most Compelling People in 2008. In her spare time she is a competitive sailor and reads to elementary school children.

To see more of Katie's outstanding art please visit her website at **www.oralart.ca**

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Introduction

Multiple sclerosis (MS) is a complex and unpredictable disease that affects approximately 55,000 to 75,000 Canadians. If you or a loved one has MS, you know there are good and bad days because MS is not a “one-size-fits-all” condition. You will find your own way of adapting, whether through the right medications, diet and exercise, or coping skills you will learn.

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

At first glance, getting a good handle on your finances may seem overwhelming. If you give yourself some time and have a little patience however, you can accomplish this step. The goal of *Adapting: Financial Planning for a Life with Multiple Sclerosis* is to help you meet the financial challenges that can accompany MS, so you can focus on living your life to its fullest.

SECTION 1: WHERE I AM TODAY

Being diagnosed with multiple sclerosis (MS) is a major event—and you may think you need to make major changes in your life right away. This can be especially true if you are going through a flare-up, or exacerbation, of your MS symptoms. As difficult as this is, don’t panic. Depending on your symptoms, you may need to do some adapting, but you probably don’t have to make major lifestyle changes immediately. If you have a job, don’t resign. If you own a home with stairs, don’t sell it yet. Instead, try to keep in mind that the majority of people with MS do not become severely disabled.

Getting Organized

Start by devoting some time to exploring, learning, and recording. First, find out as much as you can about MS. The MS Society of Canada strives to provide access to accurate, current, and comprehensive information in a number of formats to people with MS, their caregivers, family and friends. For information on multiple sclerosis, including a listing of useful publications on a variety of MS-related topics please visit www.mssociety.ca. You may also find the resources section at the back of this booklet helpful to get started.

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

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, government benefits program staff member 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?

Reaching Out for Help

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

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

Locating Important Papers and Contact Information

Important papers include the following:

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

Finding these papers can be one of the tasks given to a partner or trusted friend. Ask this person to make copies and put them in labelled file folders that you can get to easily. Reviewing your important papers may help to identify resources and assets that can help you pay for the management of your MS. In addition, use the worksheet below to list the names and phone numbers of professionals who can help you with financial questions. These professionals may include your accountant, insurance agent, social worker, financial planner, and lawyer.

My Professional Advisors

	Advisor's Name	Phone Number	E-mail Address
Accountant/tax preparer			
Social worker			
Financial planner			
Insurance agent			
Lawyer			
Other			

Taking a Financial Inventory

Review your MS journal to see if your symptoms may lead to additional expenses.

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

Next, write down an estimated value of everything you own and the dollar amount of your debts. You'll need this information as you plan for future expenses or apply for any benefits that are based on financial need. As you do this estimate, consider obtaining a professional appraisal of valuable assets, such as your home, artwork, jewellery, or other collectibles. Your accountant or other financial advisor can guide you.

Using a Health-Expense Spreadsheet

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

- ➡ Dates of hospital stays or other treatments not covered by the provincial health care system.
- ➡ Charges for prescriptions and medical supplies.
- ➡ Portions of expenses not covered by the provincial health care plan or employer/ individually-purchased benefit plan.
- ➡ Amounts and dates that you paid for health care services, and any remaining balances.
- ➡ Dates any deductibles were met, if applicable in your province.

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 below. Remember to keep copies of your supporting paperwork: doctor bills, receipts for out-of-pocket health expenses, health insurance statements, cancelled cheques, and bank statements in labelled file folders.

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

If you find possible billing errors, first try to resolve them with the hospital's billing office. Next, get in touch with the provincial ministry of health or your health insurance company. If the matter remains unresolved, contact the provincial consumer protection office or insurance regulatory agency to file a complaint. Look in the blue pages of the phone book or conduct an Internet search.

Health-Expense Spreadsheet

Date of Service/Medical Purchase	Charges	Amount/Date Paid by Health Care Plan (if applicable)	Date Deductible Met	Date Out-of-Pocket Limit Reached

Prioritizing Your Bills

MS and its related costs can strain your finances, but it is important to pay your bills on time to maintain a good credit rating. If this is not possible, decide which bills are the most important and pay them first. (For example, if you have individually-purchased health insurance, it is important to pay your insurance bill so you do not lose coverage.) You also can call the people and companies to whom you owe money. Explain your situation and ask if you can have longer to pay. Many companies have options that will give you more time or may have special programs to help you pay your bills. (For more suggestions about managing debt, see Section 3.)

Reviewing Your Health Care Benefits

Visits to doctors, hospital stays and doctor-ordered procedures, such as blood tests and many other services, are covered by your provincial/ territorial health care program. You may have additional coverage from an employer health care plan or from one that you have purchased.

As soon as possible, review your health care benefits, so you will know what the plan will cover, what is excluded, and what your out-of-pocket expenses may be. Having this information will help you plan for anticipated medical expenses and strengthen an appeal on a claim if you believe it was denied incorrectly. Health care benefit plans can be difficult to read and understand, but there are people who can help you.

For additional information about the public plan, contact your provincial ministry of health. If you have a supplemental health care plan provided through your or your spouse's employer (the term **spouse** includes common law partners of either sex), contact your employer's human resources department for additional information.

Co-Payments and Deductibles

There are times when you may have to pay for what are called co-payments or deductibles. These are additional charges which can be small or large.

Under the public health care program, as mentioned above, most expenses relating to doctor visits, hospital stays and doctor-ordered procedures are covered. However, you may have to pay extra if, for example, you choose to stay in a private room in a hospital.

Under employer or individually-purchased health care plans (known as private health care plans), there are typically co-payments for various health services or there may be a maximum that the plan will pay. For example, your health care plan may pay 80 percent of the cost of prescribed drugs. You will have to pay the other 20 percent. Or the plan may limit the amount it will pay annually for benefits such as massage or chiropractic services, e.g., an annual maximum of \$500 or \$1,000.

Your plan may require you to first pay a deductible. This is the amount you must pay each year before the plan pays any expenses. For example, if your health care plan has a \$500 deductible, you must pay the first \$500 of covered medical costs before the plan kicks in.

Covered Expenses

Regardless of the amount charged by a provider, a plan will only cover certain expenses. Make sure you know what your plan considers a “covered expense” and if your health care plan will pay it.

Pre-Existing Condition Exclusion Period

There are no exclusions for having a pre-existing condition under the public health care system. With private health care plans, you may have to wait a period of time before the plan will cover that medical condition. (A pre-existing condition is a medical problem you had before you joined a health care plan.) This length of time could be three months, six months, or one year. As a rule, a group health plan cannot make you wait more than one year unless you did not enroll in the plan when first offered, in which case the waiting period may be as long as 18 months.

Lifetime Maximums

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

Prescription Drugs

Drugs for MS can be expensive. For example, the major disease modifying therapies approved by Health Canada for relapsing remitting MS can cost between \$15,000 and \$42,000 a year. Plus, you likely will require other medications to manage the disease and its side effects.

If you do not have private health care benefits, it is important to know that all provincial governments have established public drug plans that cover significant portions of the total cost of prescription drugs. For the disease-modifying therapies and a number of symptom-management drugs, you will have to meet the established criteria. For example, you may have had to experience a certain number of relapses in the last 24 months. In addition, you may have to meet certain low income requirements.

Even if you have employer or individually-purchased health care benefits, you may have to pay part of the cost of prescription drugs. Therefore, it is important to plan for this expense. Start by finding out whether the medications you need are covered by your health care plan. Some insurers will cover the generic form of the drug but not the brand name version. This information is available in the plan's "formulary," which is a list of drugs the plan will cover. Many health care plans cover some or all of the drugs that have been shown to modify or slow the course of MS as well as symptom-management drugs.

In addition, some provincial public drug programs may help pay for the portion of the drug cost that your private drug plan does not cover. For more information, contact your provincial or territorial ministry of health or the nearest MS Society division office at **1-800-268-7582** or **www.mssociety.ca**.

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

- The companies that manufacture the major disease-modifying drugs may offer prescription drug assistance programs.
- Talk to your doctor about prescribing a less expensive drug or generic version of a brand name drug, if one exists.
- Shop for the best price—and the best pharmacy.
- If you are a veteran, you may qualify for the Veterans Independence Program (VIP) health benefits. You must enroll to receive benefits.

Applying for Veterans Affairs Canada 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 Veterans Affairs Canada (VAC). *Even if you have other health care coverage, apply for VAC benefits if you are a veteran to allow VAC to determine your eligibility.* That way, if one program does not cover all of your health care expenses, you may be able to get coverage from another. For more information on Veterans Affairs Canada please visit, **www.vac-acc.gc.ca**.

SECTION 2: MOVING FORWARD AFTER INITIAL DIAGNOSIS

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.

How the MS Society of Canada Can Help

The MS Society of Canada offers information and assistance in a variety of ways through its divisions and chapters. A number of helpful publications are available, as well as an informative website (www.mssociety.ca). MS Society publications can be obtained through division or local chapter offices. The Resources section at the end of this booklet lists other useful publications and websites. The MS Society of Canada website can put you in touch with local chapters where you can obtain information about support groups. This is an excellent way to learn more about MS, tap into local resources, and share your experiences with others who have the disease.

Employment Issues—Current Employer

People with MS often are able to continue to work long after MS is diagnosed. Keeping a job and maintaining a career aren't always easy tasks, of course. You will have to monitor your symptoms and perhaps make special adaptations to your workplace.

You also must decide when and whether to tell your employer about your MS. The following sections will help you work through these issues. You may also wish to obtain the MS Society of Canada publication, *A Guide to Employment and Income Support*, which provides comprehensive information on employment issues, as well as a separate booklet intended for employers.

What Makes the Difference?

Some people with MS remain productively employed, while others with similar levels of disability do not. According to research conducted by the National MS Society in the United States, certain factors appear to be related to job retention, including:

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

Continuing to Work

If you and your doctor agree that you can keep working, try to do so. For most people, work is about more than a paycheck and benefits (such as health care coverage). Work also provides interaction with other people, a sense of accomplishment, and a source of self-esteem. Keep in mind that depression is a common MS symptom. Depression might be the result of the chemical changes happening in the brain because of MS. However, depression also can occur when a person feels isolated, or when the weight of living with a chronic disease becomes too great. A job may help fight these feelings. Still, your MS symptoms may require changes in how you perform your job. For example, you may need to take more frequent breaks, reserve a parking space near your office building, or change the way you do your job. Canadian employers (and unions) have a legal obligation to accommodate the needs of employees (or union members) with disabilities, up to the point of undue hardship. This obligation is known as the **duty to accommodate**. It is set out in the federal Canadian Human Rights Act, Employment Equity Act and provincial human rights legislation, provincial accessibility legislation and is reinforced in several Supreme Court of Canada rulings.

Tip: Avoid making important decisions about work or anything else if you are in the middle of a relapse. Symptoms can colour your judgment. Wait until you feel better.

Deciding Whether to Tell an Employer about MS

Disclosing the Diagnosis

You are not legally required to disclose your diagnosis or discuss your medical condition with an employer – current or prospective. However, there are some occupations, the transportation industry for example, where an employer may ask you to undergo a medical exam as a condition of employment. In that case, you may have to disclose your MS diagnosis. There may be other reasons to consider telling your employer about your symptoms or disability such as:

- 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 a relapse. 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.

Before you disclose any information about your MS or symptoms to your employer or colleagues:

- Know your rights concerning disclosure.
- Consider the possible consequences of making your diagnosis public.
- Learn about job accommodation – workplace changes that make it easier for you to do your job. For detailed information about job accommodation, please see the MS Society of Canada publication, *A Guide to Employment and Income Support*.
- Know your rights about accommodation.
- Seek emotional support and technical advice from other people with MS through your local chapter or division MS Society office or online MS community.

The Canadian Human Rights Code helps protect employees with disabilities who work for the federal government or for federally-regulated companies from job discrimination; however the employer must be aware of the disability. The same applies to provincial human rights legislation.

If you do decide to tell your employer, spend some time explaining your MS symptoms. (See “My MS Journal” in Section 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 staff in the human resources department and keep copies of your performance reviews. This information will come in handy if you ever feel you are being treated unfairly at work.

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.

Employment Insurance Benefits (EI)

If you have lost your job through no fault of your own, you may be eligible for Employment Insurance (EI). You have to be looking for work or upgrading your skills to receive the benefit. Most people will need between **420 and 700 hours of work** in the qualifying period, depending upon the unemployment rate in their region. Benefits can be paid from **19 to 50 weeks**.

How much will you receive?

The basic benefit rate is 55 percent of your average insured earnings up to a yearly maximum insurable amount of \$43,200. This means you can **receive a maximum payment of \$457 per week**. Your EI payment is a taxable income, meaning federal and provincial or territorial taxes, where applicable, will be deducted.

In addition, if you have children under 18 and receive the Canada Child Tax Benefit (CCTB), [a program administered by Canada Revenue Agency (CRA)], you are eligible to receive the EI Family Supplement on your family net income up to and including \$25,921 per year. You do not have to apply for the EI Family Supplement; if you are eligible your entitlement will automatically be added to your Employment Insurance payment.

For more information and to calculate the amount of EI sickness benefits you are eligible to receive, please visit: **www.servicecanada.gc.ca**, and click on the **Employment Insurance and Regular Benefits** section of the website. You can also call toll free: **1-800-622-6232**.

El Sickness Benefits

El sickness benefits may be paid up to **15 weeks** to a person who is unable to work because of sickness, injury or quarantine. To receive sickness benefits, you are required to have worked for **600 hours** in the last **52 weeks** or since your last claim. A medical certificate must be obtained to confirm the duration of your incapacity. You are responsible for paying any fees requested by the health care professional for filling out the medical certificate.

An individual who files a claim for sickness benefits is not only required to prove that he or she is unable to work, but also that he or she would be otherwise available for work, e.g., not travelling out of the country.

Special Situations:

- You may qualify for sickness benefits even with less than **600 hours** as long as you did not stop working because of illness, injury or quarantine. In fact, if you are already receiving regular benefits, and you become ill while you are on that claim, you may receive the sickness benefits you are entitled to.
- If you are receiving sickness benefits, and you ask for maternity and parental benefits, you will want to know more about the maximum number of combined weeks of benefits you may be able to receive.

For more information, visit: www.servicecanada.gc.ca, and click on the **Employment Insurance and Regular Benefits** section of the website. You can also call toll free at **1-800-622-6232**.

Compassionate Care Benefits

Compassionate care benefits are paid to persons who have to be away from work temporarily to provide care or support to a family member who is gravely ill with a significant risk of death.

When compassionate care benefits are combined with maternity, parental and sickness benefits, you can receive up to a combined maximum of **71 weeks**. Certain conditions apply. If you are in this situation and would like to know more, please call the Service Canada information desk at **1-800-206-7218**.

Short-Term Disability Insurance

If you have to be away from work for a short period of time, you may want to take advantage of the short-term disability benefits offered under your employer or union group plan, private disability insurance policy, spouse or partner's policy or government benefits – the Employment Insurance (EI) sickness benefits.

Short-term disability usually begins when your sick days run out. Most plans pay a percentage of normal earnings, for example, 70 percent, to a specified limit. Plans typically run for 15, 26 or 52 weeks. You must report the benefit as taxable income to the Canada Revenue Agency (CRA). EI sickness benefits and other forms of EI are discussed in more detail farther along in this section.

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. Maybe your employer is cutting jobs because of a sluggish economy. Job changes still are possible after you have been diagnosed with MS, but carefully consider your options before making a decision.

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

Looking for a New Job

Here are a few suggestions for job hunting:

- ➔ Focus on what you can do, not on what you can't do. Make a list of job ideas and write your resume. You do not have to mention your MS in a job resume.
- ➔ In addition to local and national job banks or job seeking resources, check sources that focus specifically on helping people with disabilities find jobs such as Service Canada's Canada Pension Plan (CPP) Disability Vocational Rehabilitation Program or Human Resources and Social Development Canada's (HRSDC) Opportunities Fund for Persons with Disabilities.

Canada Pension Plan Disability Vocational Rehabilitation Program

The CPP vocational rehabilitation program offers career counselling, skills and education upgrading, retraining, and job search skills. To be eligible to participate in the CPP vocational rehabilitation program, you must:

- ➔ Be receiving CPP benefits.
- ➔ Be medically stable.
- ➔ Be motivated and willing to participate.
- ➔ Be considered by your doctor to be able to cope with a work-related rehabilitation program.
- ➔ Be a resident of Canada.

When you have successfully completed the program, a vocational rehabilitation specialist will help you look for a job. The job search period runs to a maximum of 12 months. You will receive the CPP disability benefit throughout the program and the job search period. If you find a job, you will continue to receive the CPP disability benefit during a three-month work trial period. After that, if you continue working regularly, your CPP disability benefit will stop. If you don't find a job, your CPP disability benefit will stop at the end of the job search period. For more information visit www.servicecanada.gc.ca.

Human Resources and Skills Development Canada's (HRSDC) Opportunities Fund for Persons with Disabilities

The Opportunities Fund for persons with disabilities can help you increase your employment skill level, integrate into the workplace through special services, arrangements or equipment tailored to meet your needs, or start your own business.

To be eligible for the Opportunities Fund for persons with disabilities, you must:

- ➔ Self-identify as having a permanent physical or mental disability that restricts your ability to perform daily activities.
- ➔ Be unemployed and seeking employment.
- ➔ Be legally entitled to work in Canada.
- ➔ Require assistance to work or become self-employed.
- ➔ Not normally be eligible for Employment Insurance benefits.

Information about the Opportunities Fund is available on the Human Resources and Skills Development Canada website – **www.hrsdc.gc.ca** – and from local Service Canada Centres.

In Quebec, the Opportunities Fund for persons with disabilities is jointly administered by Sphere-Quebec and Human Resources and Skills Development Canada. Contact Sphere-Quebec – **www.sphere-gc.ca**.

Provincial government programs

Provincial governments offer vocational rehabilitation services and local job placement services. Most provincial governments also offer wage subsidies for a limited time to companies that hire individuals with disabilities.

Private and community services and programs

Private companies and community organizations offer a range of vocational services and programs including vocational, interest and skills testing, career counseling, retraining, skills upgrading and job placement.

Independent Living Centres

Non-profit independent living centres across the country provide a wide range of services and typically are staffed by people with disabilities. Independent living centres often provide counselling and training in new skills that can help you to live as independently as possible (for example, hiring in-home help or finding accessible, affordable housing). For more information on independent living please contact Independent Living Canada at **1-613-563-2581** or visit their website at **www.ilcanada.ca**.

Job Changes and Health Care Benefit Plans

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

Generally speaking, it is not a good tactic to ask to see the details of the benefits package during the first interview, but when offered a job, ask to review the package before giving an answer. When reviewing the health care portion of the employer's benefits package, pay particular attention to the:

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

Waiting Period

Before switching to a new employer's health care plan, find out when the plan will cover you. There could be a 60-day to 90-day waiting period—or you could be covered the first day you report to work. It is possible to negotiate a shorter waiting period with your potential employer. Try to avoid a gap in your medical coverage. Such a gap could mean facing a pre-existing condition exclusion period.

Plan Benefits and Your Costs

When reviewing a health care plan, consider the following:

Coverage for MS: Make sure the health care plan will cover MS medications and other useful therapies such as massage.

Type of plan: Some employers give you a choice between different types of health care plans. Read about each type, and choose the plan that is best for a chronic condition.

Costs: If you are deciding between health care plans, compare the amount of the deductible, prescription drug coverage, your share of the premiums, and so on with the overall benefits offered by the plan. Keep in mind that an inexpensive health benefit plan may not be the least expensive in the long run for someone with potentially high drug costs or other medical needs.

Other Useful Job Benefits

Although health benefit coverage is the most important employer-paid benefit, two other valuable benefits to look for are disability insurance and life insurance. Keep in mind that employer-sponsored disability plans may exclude pre-existing conditions that could lead to a future disability, so a new employer's plan may or may not cover you some period of time, because of your MS.

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

Considering Self-Employment

Many people with MS are successfully self-employed. In fact, it may be easier to rest or attend doctor appointments when you are self-employed than when you work for an employer. Before quitting a job and taking this path however, ask yourself some serious questions, such as:

- ➔ What will happen to my health care coverage, and how much will it cost to get coverage on my own?
- ➔ What other forms of insurance does my employer provide that I will have to do without or secure on my own?
- ➔ Do I have the energy and stamina to start my own business?
- ➔ Can I live without a steady paycheck?
- ➔ Can I afford to maintain and update the business equipment I will need?
- ➔ Do I have the money necessary to start a business?
- ➔ Do I have a wide network of professionals who can make referrals to my business?

Canada Business

Canada Business is a federal government resource that provides Canadians with a wide range of information on government services, programs and regulations relevant to existing and potential business entrepreneurs. For more information visit: www.canadabusiness.ca.

MY PLAN FOR FINDING A NEW JOB

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

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

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

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

Hiring Home Help

There may be times when your MS symptoms make it difficult to take care of your home or yourself. Unfortunately, this kind of help is generally covered only to a certain extent, if at all, by provincial insurance plans. Unless the primary caregiver has a long-term care insurance policy with a home care provision, paid care will be limited to what the family can afford.

Professional nurses and therapists are usually referred or assigned by a doctor. However, home care aides and domestic assistants can be hired without consultation with a doctor. The person for whom the care is required should be involved in the interview process.

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 24.
- ➔ Your health care team, other caregivers and the MS Society of Canada can be of help in locating reliable agencies that screen and refer potential candidates.
- ➔ 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 in-home help 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 chequebook, credit cards, and other valuables under lock and key.
- ➔ If your in-home help shops for you, use cash or distribute one cheque 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 in-home help is on duty.
- ➔ If your in-home help is a family caregiver and you recognize that he or she needs assistance, please contact your local MS Society of Canada chapter or division for a list of resources including respite services.

Help at Home: Needs Assessment*

Use this worksheet as a tool to help you and your family identify your needs and how they will be met. Be very specific regarding medical needs, because a trained person must help you with some of them. Revisit this worksheet as your needs change.

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

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

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

Adapting Your Home

In addition to thinking through issues dealing with employment and hiring help, you also may need to make some changes to your home. Deciding if or how to adapt your home will depend on your symptoms. For example, if your symptoms are mild, all you may need to do is get rid of clutter or rearrange furniture so you can easily move around your house. If symptoms are more severe or frequent, ramps, wider doorways, lower countertops, or other changes may be necessary. Reviewing your MS journal may help you decide what changes are needed now.

Canada Mortgage and Housing Corporation (CMHC)

CMHC's Residential Rehabilitation Assistance Program for Persons with Disabilities (RRAP) offers financial assistance to allow homeowners and landlords to pay for modifications to make their property more accessible to persons with disabilities.

Who Can Apply?

Homeowners and landlords may qualify for assistance if the property is eligible. Your property may be eligible for RRAP-D if the property:

- ➔ is occupied, or is intended to be occupied, by a low-income person with a disability;
- ➔ is rented and the rents are less than established levels for the area; or is owned and the house is valued below a certain amount; and
- ➔ meets minimum standards of health and safety.

To find out how to apply for financial assistance or for more information about CMHC programs please call toll free at **1-800-668-2642**.

Managing Costs

Here are some ideas for managing the costs of home adaptations that are not covered by CMHC.

- ➔ **Choose a contractor carefully.** Get quotes 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.

- **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 centre 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. If landlord modification of the apartment is not possible, ask about ending your lease or look into modifying the apartment at your own expense.
- **If your landlord is unwilling to work with you**, contact your city housing department or provincial housing ministry. You could also contact the provincial human rights commission.

Paying for Assistive Devices

You've probably heard the term "assistive devices." Think of them as items that can help you do things more easily, from cooking and walking to reading and working. An assistive device could include a wheelchair or a special computer screen, or it could be a cane or an easy-to-grip door handle. Having the equipment you require can make the difference between dependence and independence. In many cases, it's a necessity, not a luxury. Here are some points to keep in mind when looking for help in paying for an assistive device:

- Know your needs. Talk to your doctor or occupational therapist. Become your own best advocate for what you need.
- Some provinces pay for a portion of assistive devices that have been prescribed by a health care professional.
- Some MS Society divisions and chapters help pay for part of the cost of assistive devices or provide loans of equipment. Call the nearest MS Society division office at **1-800-268-7582**.
- Private insurance plans may cover the cost of assistive devices if they are prescribed by a health care professional.

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:

SECTION 3: TAKING CONTROL OF 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

Monthly Income Worksheet	
Sources	Per Month
Net income	\$
Tips or bonuses	\$
Child support	\$
Spousal support/maintenance payment(s)	\$
Employment Insurance (EI)	\$
CPP Regular Benefits	\$
Retirement plan(s)	\$
Private disability insurance payments	\$
CPP Disability Benefits	\$
Interest/investment income	\$
Other	\$
	\$
	\$
Total Income:	\$

Step 2: List Expenses Per Month

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

Monthly Expenses Worksheet	
Sources	Per Month
Mortgage or rent	\$
Utilities (heat, electricity and water)	\$
Telephone, cell phone, Internet provider	\$
Groceries	\$
Transportation (bus fare, care 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 classes, alternative therapies, supplements, etc.)	\$
Dentist bills	\$
Home adaptations or improvements	\$
Clothing/uniforms	\$
Child care/child support payments	\$
Spousal support/maintenance payments	\$
Loan/credit card payments	\$
Entertainment (movies, eating out, etc.)	\$
Miscellaneous (classes, gifts, vacations, pet care, etc.)	\$
Donations	\$
Taxes	\$
Savings/retirement plan contributions	\$
Other	\$
Total Expenses	\$

* 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 Section 1.
- ➔ Make sure you apply for all available programs for which you may be eligible, including CPP disability benefits and provincial social assistance benefits.
- ➔ Ask your doctor to write prescriptions for items you may need, such as a brace, walker, or special bed. A prescription shows medical necessity, which makes it more likely that your insurance will pay for it.
- ➔ Sell unnecessary items that clutter your house.
- ➔ Put away the credit cards—and only bring them out to pay for emergencies.
- ➔ Call your local housing authority or talk to your hospital social worker if you are having trouble paying your rent. Find out if you might be eligible for subsidized housing.
- ➔ Take advantage of tax deductions and credits such as the federal Disability Tax Credit (DTC). You may be able to use the federal Disability Amount (disability tax credit) to reduce the taxes you have to pay. The DTC can be claimed by the person who is disabled or can be transferred it to a spouse, parent, child or grandparent. You apply for the Disability Tax Credit using form **T2201** which can be obtained from a Canada Revenue Canada (CRA) office, an accountant or tax lawyer or downloaded on the internet at www.cra.gc.ca. Take the form to your doctor or other “qualified practitioner” (as specified by CRA) to complete the form which you then submit to CRA.
- ➔ Certain medical treatments, devices and medications are allowable medical expenses if they are authorized by medical practitioners. You will be able to deduct them from your income for tax purposes. Keep all of the receipts for expenses related to MS. For more information go to the Canada Revenue Agency website at www.cra.gc.ca and click on *Persons with Disabilities* on the left hand menu, or you can call CRA at **1-800-959-8281**.

Coping with Debt

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

- If you owe money to several companies and are in danger of missing payments, call and ask if you can make smaller payments— at least for a while. Most businesses will be more willing to work with you if you make this call before you miss a payment.
- Organize your debts from the highest interest rate to the lowest. Make at least the minimum payment due on all the debts, but put any extra money toward the debt with the highest interest rate. When that debt is paid off, move the extra payment to the next debt with the highest interest rate. In time, you will pay off your debts and save by avoiding interest costs.
- If you owe money to many businesses, it may be time for outside help. Non-profit debt-counselling groups, such as **Credit Counselling Canada** can help you set up a repayment plan at little or no cost. Please visit www.creditcounsellingcanada.ca.
- Talk to your bank or mortgage company about extending the amortization of your mortgage in order to reduce your monthly payment. Depending on the amount of your mortgage you may be able to convert the mortgage to a line of credit and pay interest only payments. When your finances improve, you may make principle payments anytime.
- Avoid going to companies that focus only on helping with credit card debt. To get out of debt permanently, you will need a plan that takes into consideration all of your expenses.
- Consider bankruptcy as a last resort. Bankruptcy stays on your credit record for 7 to 10 years, depending on the type of bankruptcy. If you are considering bankruptcy, seek legal advice before taking any action.

Looking at Investments

You may have money in a registered retirement savings plan (RRSP), other retirement plan(s), 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 registered retirement plan, try to continue to do so. This is one of the best ways to save for your future—and provides special tax breaks. In addition, employers often match all or part of the money you save in the plan. Put at least enough money into the retirement plan to qualify for matching dollars from your employer.

Hiring a Financial Professional

If you decide to hire a financial planner to review your finances, ask someone you trust or contact the nearest chapter or division office of the MS Society of Canada to refer you to professionals who have worked with people diagnosed with MS. The first step is to understand the difference between a financial planner and stock broker. Financial planners look at your entire portfolio, including investments, tax information and risk management, whereas a stock broker focuses on trading stock for highest return from investment. For more information on financial planners please contact your bank branch or alternatively, the following organizations can provide names of financial planners in your area:

- ➔ Chartered Accountants of Canada, www.cica.ca.
- ➔ The Financial Advisors Association of Canada, www.advocis.ca.

Interviewing Financial Professionals

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

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

Setting Aside Money for Unexpected Expenses

Many financial experts advise putting aside enough money to cover your bills for three to six months. Remember sometimes it's not how much money you make, it's how much money you keep. 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 may earn more interest on this type of account than with a savings account. Most banks and investment companies offer these products. They are very safe and liquid, in other words, investment funds are immediately and easily accessible. They may be a good investment if you don't need the money for a year or so, but keep in mind you will have limited access to it if you suddenly need money. In addition, depending on where you open a money market account, it may not be insured by the federal government. Be sure to ask.
- ➔ **Guaranteed Investment Certificates (GIC).** GICs are offered by banks. The rate of interest and the term of the GIC are determined when you deposit the money. These are not as flexible since you cannot break the contract before the one, three or five year period. Interest rates are generally higher than savings and money market accounts.
- ➔ **Registered Retirement Savings Plan (RRSP).** RRSP savings can be used as a way to set money aside for emergencies. While you're in your higher income years, money can be put into the RRSP resulting in a tax refund that you have available to reinvest or to use for immediate expense. If there is a time when you have little or no income, you can withdraw money from the RRSP with little or no tax payable.
- ➔ **Tax Free Savings Accounts (TFSA).** TFSAs are another useful great savings tool. You can invest up to \$5,000 per year and pay no tax on the interest, dividend or capital gain on the investment. Tax Free Savings Accounts came into existence in 2009, so if you did not invest immediately you can invest in previous years' allowable amounts. Unlike an RRSP, money put into the TFSA is not tax deductible; however, it is also not taxable when the money is withdrawn. Most investments purchased with a TFSA include: savings account, money market, GIC, mutual fund, bonds and stocks.
- ➔ **Registered Disability Savings Plan (RDSP).** RDSP is a long-term savings plan to help Canadians with disabilities and their families save for the future. Canadian residents under the age of 60, who qualify for the Disability Tax Credit, can open an RDSP. Earnings accumulate tax-free, until you take money out of your RDSP. The RDSP is also eligible for federal government grants and bonds. The federal government pays a matching grant of up to \$3,500, depending on the amount contributed and your family income. The government also pays a bond of up to \$1,000 a year into the RDSPs of low-income and modest-income Canadians.

There is no impact on federal benefits, such as the Canada Child Tax Benefit, the Goods and Services Tax Credit, Old Age Security, and Employment Insurance. For more information on the RDSP please visit Canada Revenue Agency at www.cra.gc.ca or speak to an accountant or tax lawyer.

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:

SECTION 4: IF MS PROGRESSES

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

Leaving Work

If you no longer can perform your job because of MS, it may be time to leave work. However, it may be better to leave work gradually—just in case your condition changes for the better. The decision to leave the workplace should be considered carefully, taking into account health status, eligibility for disability and health benefits, personal and family finances, and life beyond 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 flextime or working from home.

Using EI Sickness Benefits

As detailed in Section 2, under the EI benefits you may be able to take up to 15 weeks of paid leave to care for yourself because of a serious illness.

In addition, you cannot be taken off your employer's health benefit plan during the leave. This enables you to extend the length of time you are covered under your employer's health care plan. Of course, you must continue to pay whatever portion of the health care premium you were paying prior to the leave, if applicable.

Exploring Disability Insurance Policies

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

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

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

Benefits vary, but long-term disability insurance policies provided by employers typically pay about 60 percent of your income. The plan also may have a provision requiring you to apply for CPP 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 according to your policy.** 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 cheque?
- **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, the amount you receive as a disability benefit may not always be a set percentage of your wages. This can happen when you also are receiving income from another program. The amount you receive from those programs may be subtracted from the plan's benefit amount. If you purchased your own disability policy, however, your benefit amount will not be reduced by what you receive from government programs unless you have a rider attached to your policy that provides additional benefits that stop if and when government benefits begin.
- **Taxes.** If you paid the premium for your disability insurance, the benefit is income tax free. If your employer paid the premium, the benefit is taxable. In some cases, there is a blend of employer-paid premiums and worker-paid premiums. For example, your employer may pay the premiums to cover 40 percent of your wages, but you "buy up" to cover another 20 percent. In this case, your total benefit would equal 60 percent of your income. Of that 60 percent, 40 percent would be taxable and 20 percent would not be taxable.

Managing your risk

You should note that people with MS usually do not qualify for long term disability insurance, critical illness insurance or life insurance. However, caregivers of people with MS may wish to consider purchasing such insurance for themselves. If the caregiver becomes ill or passes away, the person with MS may be greatly affected. Insurance will help provide the finances for alternate types of assistance.

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 Canada Pension Plan (CPP) disability benefits. As mentioned above, the private disability insurance plan may require you to apply for CPP disability benefits before processing your application.

The Canada Pension Plan offers disability benefits if you have a serious long-term disability that prevents you from working regularly at any job. If you work in Quebec, you contribute to the Québec Pension Plan, which is similar to the Canada Pension Plan.

The monthly benefit is made up of two parts – a flat-rate amount and an amount based on how much and for how long you paid into the CPP. It is adjusted yearly to provide for increases in the cost of living.

CPP definition of disability

The CPP definition of disability requires that the disability be severe and prolonged and prevent you from working at any job on a regular basis. It is a stricter benchmark than that for private disability insurance.

Individuals will only be considered eligible for the CPP disability benefit if a team of medical adjudicators decides that, based on your application and supporting documentation, your disability is both "severe" and "prolonged". The law defines a severe disability as one which prevents you from doing your former job, or any other job, on a regular basis. A disability is prolonged, when it is likely to be long term, of indefinite duration, or is likely to result in death.

Only people who meet all the rules in the legislation can receive a benefit. The CPP disability benefit is taxable. Your benefit will stop if your condition improves to the point where you are able to work at any job on a regular basis, or you turn 65, or upon your death. After age 65, the CPP disability benefit automatically converts to the CPP retirement pension. The CPP retirement benefit is less than the CPP disability benefit, but you are also eligible for the Old Age Security and possibly also the Guaranteed Income Supplement.

Usually people apply for EI sickness benefits first and then for CPP disability benefits, but you may apply separately for both benefits at the same time: EI sickness benefits and disability benefits from the Canada or Quebec Pension. Long-term CPP contributors (25 years plus) can qualify for CPP disability benefits if they have worked for three out of the last six years. Applicants, who have worked less than 25 years of work, must have worked four out of the past six years.

In 2009, the minimum a person was required to earn in order to qualify as having a year worked was approximately \$4,600. A strategy for someone with MS would be to ensure that he/she earned at least that amount to protect CPP disability benefits eligibility.

It is important to note that if you receive CPP disability benefits, there may also be benefits for your children. Children between 18 and 25 must be attending school full time at a recognized institution. Children under 18 do not have to be in school to be eligible.

Application

You should apply for the CPP disability benefits as soon as you become disabled and unable to work. It may take as long as three months to find out if your application has been accepted. The application kit is available online at the Human Resources and Skills Development Canada website – www.hrsdc.gc.ca, HRSDC offices across Canada or by calling **1-800-277-9914**.

The application kit includes:

- The application for disability benefits for yourself and any dependent children.
- A questionnaire for disability benefits requesting detailed information on your work history and medical condition.
- A medical report form, in which you complete Section A and your doctor completes Section B.
- An authorization/consent form, allowing Canada Pension Plan to obtain medical, vocational, educational and employment information from other parties.
- A Child Rearing Dropout Provision form for you to complete if you stopped working or reduced work hours to take care of your children when they were under the age of seven.

Quebec Pension Plan (QPP) disability benefit

The Quebec Pension Plan (QPP) disability benefit replaces a portion of your employment income if you are a resident of Quebec who is unable to work because of disability, as defined in QPP legislation. The monthly benefit is made up of two parts – a fixed amount paid to every beneficiary and a variable amount based on the employment earnings recorded under your name under the Quebec Pension Plan. The benefit is administered by the Régie des rentes du Québec.

The application for disability benefits form and medical report form are available online at the Régie des rentes du Québec website – www.rrq.gouv.qc.ca – or by calling **1-800-463-5185**.

Provincial Benefits

People who are unable to work and have little income and few assets can apply for provincial government social assistance programs as their main source of income. These benefit payments help pay for food, shelter, fuel, clothing, prescription drugs and other health services. Some provinces have a separate benefits and services for people with disabilities.

For more information, contact your provincial government ministry of community and social services (the name may vary across the country). You can find information on federal, provincial and territorial benefit programs and services on the Canada Benefits website at **www.canadabenefits.gc.ca** or call **1-800-622-6232**. You may also contact the nearest chapter or division office of the MS Society of Canada.

Returning to Work

Many people with disabilities want to return to work, and the CPP disability benefits provides a number of ways in which individuals can test their ability to work again while still receiving benefits.

First, individuals who receive CPP disability benefits can earn up to \$4,600 (before taxes) as of 2009 without informing Service Canada staff and without losing the benefit. This amount may increase in future years.

Second, the CPP disability benefits program offers automatic reinstatement to people who receive CPP disability benefits and decide to return to work. If the disability recurs within two years and you can't continue working, your CPP disability benefits will be quickly re-started upon request; you will not have to re-qualify.

Third, if you are receiving CPP disability benefits and believe you can work on a regular basis, you may be eligible for the CPP vocational rehabilitation program. Service Canada pays for the program for all of those who qualify. For more information contact Service Canada at **1-800-277-9914** or visit Service Canada website at **www.servicecanada.gc.ca**. You may also find the MS Society of Canada publication *A Guide to Employment and Income Support* helpful.

Tapping into Other Sources of Income

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

- ➔ **Retirement plan.** You can withdraw money from your RRSPs. This may be an economically wise option during years of low or no income as withdrawals are taxed as income. You may be able to borrow money from a retirement plan at work. Or, if you are permanently disabled, you can withdraw money from a retirement plan without facing a penalty, but you must pay income tax on the amount withdrawn. Remember, people with MS have a near-normal life expectancy, so be careful about using the funds set aside for retirement.
- ➔ **Veterans Affairs Canada benefits.** If you are veteran, make sure you enroll in the VAC health care system. You may receive benefits for your disability beyond those provided by CPP disability benefits or private disability insurance. For more information, go to www.vac.gc.ca or call **1-866-522-2122**.
- ➔ **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.
- ➔ **Critical illness insurance.** Critical illness insurance provides financial aid to individual diagnosed with an illness. Critical illness insurance can be expensive however it has tremendous flexibility in what it can be used for. You do not have to get approvals for expenditures or provide receipts. It can be extremely helpful in situations where caregivers are not able to provide assistance; funds from this type of insurance will ensure ongoing care for the person living with MS.
- ➔ **Mortgage or credit disability insurance.** This kind of insurance might pay your mortgage or credit card bill if you are disabled. If you do not already have this type of insurance, it is unlikely you would qualify to purchase it at standard rates.
- ➔ **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 60 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.

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 disability benefits:

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

MS is not a fatal disease. However, mortality is a fact for all of us—and loved ones will be left behind. This is why estate planning is a good idea for everyone. Make it a matter of routine to revisit your life insurance and estate planning needs periodically. Addressing these issues shows that you care about your loved ones' future.

Life Insurance

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

- ➡ Are you single or do you have a spouse or partner?
- ➡ Does your spouse or partner work, and is he or she self-supporting?
- ➡ Do you have any dependent children?
- ➡ Do any of your children have special needs, such as learning disabilities or serious health conditions?
- ➡ Do you have elderly parents who rely on you for financial support?
- ➡ How much money have you set aside in relatively safe investments?

Because of MS, you will not be able to buy life insurance at standard rates. However, your employer may allow you to buy additional life insurance above the amount the company provides. If you change jobs, try to convert your group life insurance policy into an individual policy. A financial planner or insurance agent can answer your life insurance questions. You may find the MS Society of Canada publication *Insuring Your Future: Your guide to life insurance and multiple sclerosis* helpful. Please also see the resource section at the back of this booklet for additional resources about life insurance.

Estate Planning Paperwork

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

When hiring a lawyer, interview several before making a decision. Ask if the lawyer has experience in working with people with disabilities and experience in estate planning. Find out what the lawyer charges and what you can do to keep your costs down.

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

Will

You should have a will, and if you are married, your spouse should have one, too.

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

Beneficiaries

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

Durable Power of Attorney

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

Health Care Proxy and Living Will

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

My Plan for Handling Estate Issues

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

2. I have the following documents in place:

Will: Yes _____ No _____

Beneficiary designations: Yes _____ No _____

Power of attorney: Yes _____ No _____

Health care proxy: Yes _____ No _____

Living will: Yes _____ No _____

Continuing to Care for Yourself and Your Family

Wellness is a concept that does not normally come to mind when we think about MS. We usually think in terms of curable or incurable. MS belies this concept in many ways. It is indeed incurable at the present time; however, it is a complex condition that yields to many treatments and therapies. Although they are not cures, they can provide you with at least some control over your wellness.

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

- ➔ Continue your medications.
- ➔ Talk openly with your doctor about MS-related symptoms, such as depression or sexual problems. Treatments may be available. The MS Society of Canada maintains a comprehensive library of booklets on various topics related to multiple sclerosis. For a list of MS Society of Canada booklets please contact your local MS Society of Canada office or visit www.mssociety.ca.
- ➔ Accomplish what you can—when you can. You may have small bursts of energy. Use some of them just to have fun with your loved ones.
- ➔ Find exercise routines that work for you. Look into such options as tai chi, aquatic therapy, yoga, or Pilates. Ask a friend or family member to join you. Exercise builds strength and flexibility—and fights depression.
- ➔ Contribute where you can. Many nonprofit groups would appreciate your help, even if it's only for an hour or two at a time. Volunteering can give you a break from thinking about MS.
- ➔ Keep your mind active. Read to your children. Do crossword puzzles. Take a class. Mental activities keep the mind flexible and fight cognitive problems.
- ➔ Use mobility devices if they help. Isolation can easily lead to depression. Get out of the house when possible, join family outings, and interact with others.
- ➔ Discover coping techniques. Meditation, prayer, or biofeedback can calm the mind and decrease the fear that comes with MS.
- ➔ Take advantage of every resource available to you, ask your MS Society of Canada chapter or division for a listing of local resources.

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

CONCLUSION

This booklet has covered many topics—from assessing your current health care coverage to estate planning. We hope that you have found the booklet useful and will refer to it often as you adapt to the changes that accompany MS.

Living life to the fullest is the best way to fight MS.

RESOURCES

Other Multiple Sclerosis Society of Canada booklets related to financial planning and MS include:

- ➔ *A Guide to Employment and Income Support*
- ➔ *Insuring Your Future: A guide to life insurance and multiple sclerosis*
- ➔ *A Guide for Caregivers*

To obtain copies of these, or other MS Society of Canada publications, please contact your local MS Society chapter or division, or call **1-800-268-7582**. You can also view all MS Society of Canada publications online at **www.mssociety.ca**.

Further Reading

Disclosure: The Basic Facts, published by NMSS. Call **1-800-344-4867** or go to **www.nationalmssociety.org**. Click on Living with MS, and go to Library & Literature and Brochures.

Should I Work? Information for Employees, published by NMSS. Call **1-800-344-4867** or go to **www.nationalmssociety.org**. Click on Living with MS, and go to Library & Literature and Brochures.

Hiring Help at Home: The Basic Facts, published by NMSS. To access this resource, visit **www.nationalmssociety.org**, click on Living with MS, and go to Library & Literature and Brochures.

At Home with MS: Adapting Your Environment, published by NMSS. Call **1-800-344-4867** or go to **www.nationalmssociety.org**. Click on Living with MS, and go to Library & Literature and Brochures.

Organizations and Useful Websites

Federal Government

Canada Mortgage and Housing Corporation (CMHC)

Among other programs and services, CMHC provides financial assistance for accessibility work to modify dwellings occupied or intended for occupancy by low-income persons with disabilities.

Toll-free: **1-800-668-2642**

Website: **www.cmhc-schl.gc.ca**

Canada Revenue Agency (CRA)

CRA administers tax laws for the Canadian Government and for most provinces and territories as well as various social and economical benefit and incentive programs delivered through the tax system.

Toll-free: **1-800-959-8281**

Website: **www.cra.gc.ca**

Human Resources and Skills Development Canada (HRSDC)

HRSDC offers information on career planning, financial benefits, labour and workplace training and learning.

Toll-free: (general inquiries): **1-800-622-6232**

Website: **www.hrsdc.gc.ca**

Industry Canada

IC provides a variety of programs and services for Canadian businesses and consumers.

Toll-free: **1-866-959-1699**

Website: **www.ic.gc.ca**

EMPLOYMENT AND TRAINING

Canadian Council on Rehabilitation and Work (CCRW)

CCRW is a national organization supporting individuals with disabilities, employers and community agencies in advancing employment.

Toll-free: **1-800-664-0925**

Website: **www.ccrw.org**

The Vocational Rehabilitation Association of Canada (VRA Canada)

VRA Canada is a national organization that partners with other professionals to deliver timely and effective vocational rehabilitation services that help individuals with impaired work capacity to improve their quality of life.

Toll-free: **1-888-876-9992 x202**

Website: **www.vracanada.com**

Independent Living Canada (IL)

IL Canada is a national non-profit association of Independent Living Centres run by and for people with disabilities who promote the Independent Living Philosophy.

Telephone: **(613) 563-2581**

Website: **www.ilcanada.ca**

FINANCES, INVESTMENTS AND INSURANCE

Advocis® The Financial Advisors Association of Canada

Advocis® is a national professional association that prepares, promotes and protects financial advisors in the public interest. Select Consumer info on the Advocis website for financial resources and tools as well as a listing of local financial advisors.

Website: www.advocis.ca

Canadian Association of Credit Counselling Services (CACCS)

CACCS is a national association that provides financial counselling education, accreditation of agencies and certification of Credit Counsellors. A listing of accredited not-for-profit credit counselling agencies across Canada can be located on the CACCS.

Website: www.caccs.ca

Canadian Life and Health Insurance Association (CLHIA)

This non-profit association has a variety of free publications that discuss many aspects of life insurance.

Website: www.clhia.ca

Chartered Accountants of Canada (CICA)

CICA is a national organization that represents Canadian chartered accountants while protecting public interest. A comprehensive list of chartered accountants and accounting firms is provided on the CICA website in the section titled Provincial Institutes/Ordre.

Website: www.cica.ca

Insurance Canada

An internet source of information for consumers, professionals and businesses about insurance related topics.

Website: www.insurance-canada.ca

Investor Education Fund (IEF)

IEF is a non-profit organization that develops and promotes unbiased, independent financial information, programs and tools to help consumers make better financial and investing decisions.

Website: www.GetSmarterAboutMoney.ca

How to reach the MS Society of Canada

Current as of January, 2010

Call toll-free in Canada: 1-800-268-7582
www.mssociety.ca

British Columbia Division

1501-4330 Kingsway
Burnaby, British Columbia
V5H 4G7
(604) 689-3144
info.bc@mssociety.ca

Alberta Division

#150, 9405 - 50 Street
Edmonton, Alberta
T6B 2T4
(780) 463-1190
info.alberta@mssociety.ca

Saskatchewan Division

150 Albert Street
Regina, Saskatchewan
S4R 2N2
(306) 522-5600
info.sask@mssociety.ca

Manitoba Division

100-1465 Buffalo Place
Winnipeg, Manitoba
R3T 1L8
(204) 943-9595
info.manitoba@mssociety.ca

Ontario Division

175 Bloor Street East
Suite 700, North Tower
Toronto, Ontario
M4W 3R8
(416) 922-6065
info.ontario@mssociety.ca

Quebec Division

550 Sherbrooke Street West
Suite 1010, East Tower
Montréal, Québec
H3A 1B9
(514) 849-7591
info.qc@mssociety.ca

Atlantic Division

71 Ilsley Avenue, Unit 12
Dartmouth, Nova Scotia
B3B 1L5
(902) 468-8230
info.atlantic@mssociety.ca

National Office

175 Bloor Street East
Suite 700, North Tower
Toronto, Ontario
M4W 3R8
(416) 922-6065
info@mssociety.ca



Contact the Multiple Sclerosis Society of Canada:

Toll-free in Canada: 1-800-268-7582

Email: info@mssociety.ca

Website: www.mssociety.ca

Our Mission

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.



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