

CHAPTER 9

Dealing with Health Insurance and Financial Concerns

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MS AND FINANCIAL CHALLENGES

As a person with multiple sclerosis (MS), you may be in early or mid-career at the time of your diagnosis. The initial decisions you make may include choices about continuing to work and maintaining your financial status. For most of you, this is obviously your best financial position. The following questions may seem obvious, but they are worth asking because their importance cannot be overstated. While you are working toward medical stabilization, have you used all of your available sick leave and vacation time? If you can work part-time or several days a week, have you spread out your vacation and sick days to the best of your ability? Perhaps some of your colleagues could donate some of their sick leave to you? Have you been creative with your Family and Medical Leave Act (FMLA) time? Note that some states offer disability leave that will pay a percentage of your salary while you are recuperating. Check with your local WorkSource office.

If the best efforts have been made medically and you've gone through the decision-making process described in chapter 8 and decided you are no longer able to stay at your job, then there still are a number of issues that must be handled. Your health insurance is, of course, of primary concern. Your company may have short- and long-term disability insurance, and this income stream must be considered. Then, the effort to secure Social Security benefits, that is, Social Security Disability Income (SSDI) for those with work experience or Supplemental Security Income (SSI) for those who were not working or have no extended work experience, must be considered.

Other issues relate to considering part-time work as a supplement to your SSDI subsidy and any work-related expenses that can reduce your income and, therefore, leave your Social Security benefits intact. Some of you must simply work toward establishing a “bottom line” of monthly financial assets and income stream versus mandatory debt. In sum, there are many issues to be considered in the financial planning area and dealing with these issues is the focus of this chapter.

KEEPING YOUR JOB

From a financial perspective, the initial focus for most of you will be on keeping your job. How much vacation and sick leave can you use? Does your company have short- and long-term disability insurance you can use? Could you let it be known through the employee network that you’d appreciate some donated sick leave time from colleagues? Can you meet the requirements for the Family and Medical Leave Act (FMLA) to tap into more time (albeit unpaid) in order to keep your job? The basic point here is that there are a number of options to be considered before you give up on a job that is meaningful and financially rewarding to you.

SHORT- AND LONG-TERM DISABILITY INSURANCE

The availability of support under disability insurance programs depends on the type of program to which your employer subscribes. Short-term disability programs usually provide coverage of 60 to 80 percent of salary for a period of time that can range from three months to two years. Long-term disability usually extends from short-term disability to retirement, but you will be required to apply for Social Security benefits, which when secured, are usually deducted from your benefits. For example, if your long-term disability insurance check is \$2,000 per month and you obtain SSDI benefits of \$1,100 per month, your long-term disability insurance payout will be reduced to \$900 per month, bringing the total to the \$2,000 per month that the insurer originally guaranteed to you.

HEALTH INSURANCE CONCERNS

If you do leave your job, obviously, health insurance coverage will be a major concern. There are a range of insurance options that may be available to you that are important to understand. They are discussed below.

The Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985

COBRA is a law requiring employers who offer group health insurance coverage to their employees to provide a continuation of their insurance after an employee’s termination for a specified length of time. This Act usually covers the health plans of employers with twenty or more employees who have worked at least 50 percent of the workdays in the prior calendar year.

The insurance premiums of the terminated employee are paid at the company's group rate. COBRA benefits also extend to the spouse and dependents of the terminated employee. COBRA benefits are available for eighteen months after termination and may be extended for an additional eleven months in the event of disability.

You, your spouse, and your dependents may not be eligible for COBRA if you were not yet eligible for the group insurance program, were terminated due to gross misconduct, had declined group insurance coverage, or became eligible for Medicare. Spouses of former employees lose coverage if they divorce or separate or the former employee dies.

Health Insurance Portability and Accountability Act (HIPAA) of 1996

The emphasis of this Act was to provide access to group health plans for workers who wish to change jobs or are terminated. The coverage includes medical, dental, vision, prescription drugs, flexible spending accounts, and some employee/assistance plans. HIPAA limits exclusions for preexisting medical conditions that could force you to stay with the company that employs you. It also prohibits discrimination based on your disability and health status in the area of group insurance coverage.

Essentially, HIPAA establishes that if you were insured during the previous twelve months, you will have no waiting period under any new employer's group plan. You must, however, have been treated for your medical condition, in this case multiple sclerosis (MS), in the six-month period preceding new plan enrollment. You don't necessarily have to have seen your physician, but you would have had to be taking some medication or receiving treatment.

If you were not insured in the twelve months prior to applying for the new employer's insurance plan, your longest waiting period should be only twelve months. HIPAA also requires the issuance of a Certificate of Coverage for evidence of coverage of your preexisting condition to expedite coverage with your new insurer.

Individual Insurance Plans

If you have no new employer-insurance options and you've exhausted your COBRA benefits, a number of private medical insurance options may be available in your state. Acceptance is based on a point total from the new insurer's medical questionnaire. Monthly premium costs are based on your age and the deductible (e.g., \$500, \$1,000, etc.). The higher the deductible, the lower the premium. If you are rejected from assignment to one of these plans, you may then be eligible for state health insurance pools maintained by the majority of states for individuals considered to be high risk.

State Health Insurance for High Risk Individuals

If you are denied health insurance as a *high-risk* cost person, most states administer a high-risk health insurance pool. These programs provide insurance coverage and can provide it at a more reasonable rate than other insurers. Although eligibility can vary by state, many states use the federal standards of eligibility. Federal standards of eligibility include the following:

- You have exhausted your COBRA/state program benefits

- You had at least eighteen months of prior coverage under a group health or government insurance plan
- You are a resident of the state in which you are applying
- You are not eligible for coverage under a group health plan, Medicare, or Medicaid
- You have no break in health insurance coverage for sixty-three or more days from the termination of your previous insurance

Monthly costs of these plans can vary and they can have relatively expensive annual deductibles with high premium costs. Some plans are secondary to Medicare and have no deductible. For more information, contact your state's insurance commission.

Basic Health Insurance Plans

Basic health insurance plans are available in some states if you meet the criteria for low income. Premium costs are very moderate, but due to the recessionary economic conditions in many states the availability of these plans can be limited, or waiting lists can be exceptionally long.

What If You Run Out of Options?

In some instances, due to eligibility criteria, financial status, extended wait lists, and so on, you may run out of health insurance options. Having MS, it is critical that you maintain your medical care and medication. Outside of borrowing money from your friends and family to pay for your medical coverage (remember, you are a very worthwhile cause!), you may need to seek treatment at a city or county public health clinic. If you are a veteran, you may qualify for treatment at a Veterans Administration hospital if you meet various criteria.

Some of these clinical settings may be able to provide you with medication, but this is likely to be only on a short-term basis. It may be of greatest benefit for you to apply directly to the pharmaceutical maker of the medication recommended by your physician (see company contact information in table 1.1 in chapter 1.) Different pharmaceutical companies will have grant programs at varying times. Some university MS clinics will be evaluating different medications in clinical research programs. If you are enrolled in such a program and a medication is effective for you within this program, it's likely that the pharmaceutical company will maintain you on the medication regimen, at no additional cost if necessary. Contact the National Multiple Sclerosis Society (NMSS) or its local chapter for more ideas in this area. In terms of receiving adequate medical treatment, tenacity and creativity go a long way. Enlist your friends, spouses, and significant others in this effort.

Health Insurance Pros and Cons

If you find yourself in a health insurance coverage crisis, here is a worksheet to use while you consider and review the different avenues of health insurance coverage that may meet your needs.

WORKSHEET 18: MAINTAINING MEDICAL CARE

1. Somehow maintain last employer's insurance

Pro(s) _____

Con(s) _____

2. Change job, use HIPAA to secure new insurance

Pro(s) _____

Con(s) _____

3. Use COBRA to extend benefits from last employer

Pro(s) _____

Con(s) _____

4. Apply for insurance from state insurance pool for high-risk individuals

Pro(s) _____

Con(s) _____

5. Apply for state basic health plan for low-income people

Pro(s) _____

Con(s) _____

6. Seek medical care through county/city health clinics or the Veterans Administration

Pro(s) _____

Con(s) _____

7. Seek available medication through pharmaceutical company grants/university research programs

Pro(s) _____

Con(s) _____

Evaluating Your Health Insurance Policy

As many readers already know, health insurance policies can vary widely in coverage and restrictions. Working with the following worksheet should help you understand some critical aspects of your health insurance:

WORKSHEET 19: EVALUATING YOUR HEALTH CARE POLICY

What is the extent of the critical services that you need covered and how much is the deductible for each treatment or on an annual basis? _____

What is your co-pay structure? _____

What are the specifics of your pharmacy coverage? _____

Are there financial limits on length of hospitalization, tests, number of physicians' visits, surgery, and other specialized services? _____

Are certain medical interventions specifically excluded or simply not covered? _____

What are your choices regarding the providers you can see? _____

Long-Term Care

If you anticipate a need for long-term care, there is another type of policy that you should explore. That is, you should try to secure a policy with a fixed premium and an inflation rider that adjusts the benefit rate to the time of use. All levels of care should be covered in this policy and reimbursement should be provided for the actual cost of services versus a fixed sum. Look for policies with short waiting periods for coverage (100 days or less) and offering four or more years of nursing home coverage. For many of you with MS, long-term care coverage very obviously falls into the category of luxury. For others, however—those who are alone or don't wish to impose the burden of their care on their families, and can afford it—long-term care can be a very worthwhile option.

MAINTAINING YOUR INCOME STREAM

Aside from your health insurance coverage concerns, there are many other basic income stream considerations that are important for you. These include how you handle your existing debt, the value of your short- and perhaps long-term disability income, the amount you will actually receive in monthly Social Security benefits, your pension structure, and the amount that you can tap into from your Individual Retirement Account (IRA) or Keogh program.

If you are not working, your daily expenditures will decrease, but, obviously, you will not receive a salary. For most mid-career persons who leave work, their income stream will be some combination of short/long-term disability, pension or IRA/Keogh, some savings, and, eventually, Social Security benefits that may take some time to secure (see chapter 11 on the application process for Social Security and strategies to employ when applying).

DEBT CONSOLIDATION/REDUCTION

If you have significant debt, your first step should be to reduce your high-interest obligations, such as credit card debts and personal loans. This would involve paying off as much of the debt as is possible, transferring to new credit cards at lower introductory rates, or negotiating *extended fixed payments without increasing the interest*. You simply don't want to be in the position of paying the minimal interest or nominal monthly payment amounts with no substantial payments to the balance of the principal that you owe. If you have many debts, it might be wise for you to consult a credit counseling service that will help you consolidate your debt into a payment to be distributed by them to your creditors. Bankruptcy options, such as chapter 7 liquidation bankruptcies or chapter 13 repayment plans, are available through a lawyer or legal aid association, but most creditors will agree to a fixed nominal payment schedule versus significant losses if you choose the bankruptcy option. Under the Bush Administration's bankruptcy reform bill, S. 256, however, Chapter 7 "start fresh" bankruptcies will be reduced due to filing requirements and you will need a lawyer. Chapter 13 requires payment of some debts by order of a judge according to the debtor's resources. You will be required to see a credit counselor both before filing and prior to discharge of debt under either chapter. Of course, bankruptcy should be viewed as a last resort because it will have a severe impact on your ability to secure credit or financing in the future.

SOCIAL SECURITY PROGRAMS

If you have a substantive work background, Social Security Disability Income (SSDI) is available to you as a monthly subsidy if you meet eligibility criteria. To obtain SSDI, your disability must prevent you from what is called "substantial gainful activity," meaning that you earn less than \$830 per month (\$1,310 per month if you are blind). These amounts will be periodically adjusted upward. You can reduce your evaluated earnings by having an Impairment-Related Work Expenses (IWRE) plan.

Supplemental Security Income (SSI) is available for individuals who haven't worked or earned the required number of work credits. Your SSI payment is reduced dollar for dollar with any money you earn (unless you can reduce income due to your work-related expenses on a Plan for Achieving Self-Support [PASS] plan). If you are eligible to receive SSI, you will immediately become eligible for Medicaid

benefits. **Note:** You are likely to be more successful in receiving Social Security support if you follow the procedures outlined in chapter 11.

SECURING MEDICAID FOR LONG-TERM CARE: USE OF AN INCOME CAP TRUST

If you are in need of long-term care, nursing home costs and other forms of long-term assisted living can completely drain your available income and savings. However, if you engage a lawyer to establish an income cap trust and thus take control of any income or savings that you have in excess of the amount that would require you to be cut off from Medicaid, you can then qualify for Medicaid. Your excess funds will be held in the trust and can be used only for special needs, e.g., a motorized scooter, special transportation costs, an enlarged computer screen, a voice-activated computer, a cell phone due to medical necessity, and so on. Your available income up to the amount of the Medicaid cutoff will be for a personal needs allowance, a community spouse income allowance, and medical needs not covered by Medicaid in the nursing home. The state will pay the rest of the monies to the nursing facility.

Obviously, the purpose of the income cap trust is to change the manner in which Medicaid assesses your available income by eliminating from consideration the income that would render you ineligible for Medicaid. If you are unable to pay for long-term care, this may be the best avenue for you to pursue. **Note:** It is important to understand, however, that after your death the state becomes entitled to the proceeds from the trust. You will not be able to leave monies to your spouse, significant other, or your children. If you feel mentally capable, you may be able to establish this trust for yourself and make decisions about it. In other cases, an attorney or conservator (spouse, significant other, or family friend) might be the best choice for the trustee. Regulations on these trusts vary by state and it can be helpful to consult with an attorney familiar with state law. You should also contact your state Medicaid agency. (See the Resources section in the back for a Web address.)

If you have no assets (less than \$2,000) and minimal income, you could be eligible for Medicaid for long-term care support. When your need for physical care is less substantial and you do not require twenty-four-hour physical care, you can seek community home-care support through your state health and human resources agency. Through this mechanism you can be supported in your home until twenty-four-hour residential care might be needed. This involves a state waiver to allow use of Medicaid funds for in-home care. Financial eligibility requirements, although similar to long-term care, will vary support somewhat from state to state.

STRUCTURING YOUR PENSION AND RETIREMENT SAVINGS

You may be in a position in which you have significant savings, an IRA/Keogh Plan, a pension payout, and so forth—basically a significant amount of money that must be used wisely. You'll need to consider structuring how you'll use these funds based not only upon the amount of funds available, but also upon your medical prognosis. If your physician's prognosis for your capacities over time is relatively "stable" and you need to depend on a steady income stream, you might want to consider purchasing a lifetime annuity guaranteeing a stable income.

If you have chronic progressive MS and you anticipate the need to seek nursing home care under Medicaid, you might be in a “spend down” mode in relation to your expenses. It’s important to remember that if you meet the IRS code definition for disability under Section 72 (because you are unable to work due to a disability that would result in death, or of long and indefinite duration), the 10-percent penalty will be waived for prematurely taking funds out of your employer’s retirement fund. This does not apply, however, to your personal IRA/Keogh plan. With your physician providing you with a medical prognosis, it can be very helpful to discuss options for optimal distribution or investment of your retirement savings with an accountant or certified financial planner (CFP). Ideally, you should consult with an independent CFP at an hourly rate.

INCOME TAX CONSIDERATIONS

If your MS is severe enough to meet the IRS definition of disability, you will be eligible for the Elderly and Permanently and Totally Disabled Tax Credit. If you are under sixty-five, you must have retired on disability leave for permanent or total disability before the end of the tax year in which you retired. This 15-percent credit (which lowers your actual tax bill by 15 percent) is applied after subtracting all nontaxable government benefits.

It is important that all medical expenses exceeding 7.5 percent of your adjusted gross income (AGI) are documented, because such expenses are tax deductible. This obviously relates to direct medical care and medication, but other disability-related costs must also be considered. That is, include attendant care/travel for medical care (check specific allowances here), home modifications, the need for extra living space for an attendant, or various kinds of assistive technology. That technology can involve a wide range of aids from enlarged computer screens to voice-activated software that can be directly linked to improving your functional capacity in your own home.

Social Security IRWE and PASS Plans

If you are on Social Security Disability Income (SSDI) and wish to work part-time, the cost of Impairment-Related Work Expenses (IRWEs) can be used as an offset to your income, e.g., the cost of a driver to get you, the worker, to your job or of an air-conditioned system that enables you to function in your office.

If the costs of these “assists” on a monthly basis reduce your salary to under \$830 a month, you are not considered as being involved in substantial gainful activity (SGA). It should be noted that, when using your nine-month Trial Work Period (a time-limited period in which you can earn in excess of \$830 a month to explore your work capacity), you are also not considered as being involved in SGA. If you are receiving Supplemental Security Income (SSI), a Plan for Achieving Self-Support (PASS) can be developed which similarly offsets income with the costs of the ancillary services and assistive technologies that enable you to work. You should consult a state vocational rehabilitation counselor or advocate from a local multiple sclerosis association who can help you develop these plans. Or you can hire a specialist who will do the same.

It is also of interest that certain subsidies received for being a volunteer, e.g., an Americorps (former Vista program) volunteer, are not considered taxable income. You may be able to secure an Americorps position, e.g., a literary counselor in a secondary school, and receive a subsidy of approximately \$850 per month that will not be considered substantial gainful activity. Read Kurt’s story below to see how this works.

Kurt's Story

Kurt is a fifty-two-year-old former loan officer who can no longer work full-time. He applied for and receives SSDI, but he is still able to work part-time doing loan processing.

Kurt's SSDI: \$1,275 per month

Part-time earnings in mortgage processing: \$1,400

Cost of driver/aide (Impairment-Related Work Expenses): \$775 per month

Reduced Earnings = \$775; Total: = \$1900 monthly take-home

The cost of an aide who helps him get ready for work and drives him to a suburban bank is \$775. This reduces his taxable earnings due to the IRWE as in the example. Kurt enjoys his work and, although the driver is expensive, he enjoys the flexible access to a ride to work and not having to deal with public transportation.

FINANCIAL PLANNING

Before you meet with your accountant or financial planner, it is critical to accurately and realistically assess your financial picture. It's sort of like putting all your cards on the table. You might use the same form as shown in worksheet 20 below or another, but you should do one for your current situation (especially if you're still working), one if you leave work, and another that would estimate your financial position five to ten years from today.

On worksheet 20, potential resources, such as your home equity, are listed at the end of the Assets section because these can be tapped for cash resources, if needed. As an example, in the case of a house in which you have significant equity, you might use a line of credit on your house or a reverse mortgage that can provide a monthly income stream from a bank. The bank will collect the loaned amount later at the time when your house is sold. In this manner, you may be enabled to stay in your house as long as possible.

When completing the worksheet, include your spouse's or significant other's income if that applies as an asset. The issue is how much money is available to you or how much could you "tap" on a *monthly* basis. Think outside the box; for example, could you rent out a room in your home? Would your income/available funds be so low that you might become eligible for Section 8 housing or other low-cost housing? Are there certain staples that you can get every month from a local food bank? It's important to be candid with your financial planner during your discussion of your options.

WORKSHEET 20: ASSESSING YOUR FINANCIAL STATUS

Current Monthly Assets

TAXABLE INCOME

Salary/Wages _____
 Dividends/Interest _____
 Other Taxable Income _____
 Alimony _____
 Business Earnings _____
 Property/Room Rental Income _____
 IRA/Keogh Payments _____
 Annuity/Pension Payments _____

NONTAXABLE INCOME

Social Security (after potential _____
 application of IRWE/PASS Plan)
 Disability Benefits _____
 Other Nontaxable Income _____
 Other Nontaxable Subsidy _____
Total Monthly Available Income _____

Assets That Could Be Used

Stocks _____
 Savings/CD _____
 Bonds _____
 Current Equity in Home/Reverse _____
 Mortgage Availability _____
 Money Market _____
 Checking _____

Life Insurance (Net Cash Value) _____
 Automobile (Net Value) _____
 Inheritance _____
 Other Net Assets _____
 (e.g., art, furniture, etc.)
Total Available Equity _____

Monthly Expenditures

Mortgage/Rent _____
 (average, not covered)
 Auto Payment _____
 Credit Card Payments _____

 Home Insurance _____
 Medical Insurance _____
 Life Insurance _____
 Medical Expenditures _____
 (average, not covered)
 Dental Expenses _____
 (average, not covered)

Eye Care Expenses _____
 Support of Children _____
 Tuition Costs _____
 Mandatory Expenses _____
 Food _____
 Electricity _____
 Phone(s) _____
 Water/Sewer _____
 Other _____
Total Monthly Expenses _____

In relation to the monthly expenses chart, it is important to assess whether any monthly expenses could be eliminated or drastically reduced by tapping home equity or other resources, specifically credit-card debt and interest payments. Based on your eligibility, could you also reduce your costs by obtaining food stamps or using a local food bank? Is your life insurance plan critical or would a different form of coverage, such as term insurance, be less costly? Would a different car be more economical? Again, be creative. As one of our clients noted, “I am doing well financially because I am honest with myself and budget!” He has secured SSDI, pays only \$200 a month for a big, pleasant apartment on Section 8 housing, and does some part-time bookkeeping at home earning several hundred dollars a month. He plans, works, and lives within his means.

Conclusion

We hope that this chapter encourages you to tackle some of your tough financial issues if you haven't already done so. Seek help from financial planners, or reputable credit assistance agencies, local multiple sclerosis associations, and other helping professionals whenever possible. It's important to try to secure as much control over your finances as you can. It's important because difficulties or actual chaos in this area can be a significant stressor or emotional drain, not only on yourself, but on your significant others, as well. We send our very best to you as you successfully take control of your life in this important area of your finances.