



Maximizing Your
**EMPLOYMENT
OPTIONS**
and
**FINANCIAL
SECURITY**

KAREN, DIAGNOSED IN 2007

Now that you have had some time to react to your recent MS diagnosis and learn a bit about the disease, you are probably concerned about how MS might affect your working life and financial situation in the years ahead. The beginning of this chapter focuses on the steps you can take to maximize your employment options now and in the future; the rest of the chapter offers financial planning tips and strategies for optimizing your financial future.

Employment — making choices that are right for you

You may already have missed some days of work because of symptoms or medical appointments, and you may be worried about how you will learn to balance the demands of your job with the demands of the illness. Your work activities take up a significant portion of your day, contribute to your family's support and well-being — and perhaps health insurance coverage — and provide you with feelings of pride and satisfaction. And don't overlook the fact that your employment status contributes significantly to your self-image and self-esteem. Decisions about your working life should not be made hastily.

Until recently, people diagnosed with MS were often told by well-meaning

family and friends — and even by their healthcare providers — that they should leave their jobs and stay home and rest. The unfortunate message was that people with MS could no longer manage the demands of work or make meaningful contributions in their chosen fields. Times have changed. Within the last several years, there have been a number of advances both in the management of MS and in society's attitudes towards individuals with disabilities. A range of medications and management strategies exist to help people deal with their symptoms, and treatments are now available to reduce the number of exacerbations and slow disease progression. The Americans with Disabilities Act (ADA) works to define and protect the civil rights of all individuals with chronic illness and disability. And, most importantly, the attitudes of employers and employees are undergoing a change. There is increased recognition of the contributions made by workers with disabilities who stay on the job.

“My work is important to me. How can I maximize my options for the future?”

As you think about your employment situation, keep in mind that you can remain employed as long as you want to and are able. There is no reason for you, or anyone else, to assume that you need to leave the workforce because you have been diagnosed with MS. The keys to continued employment with any kind of limitation or disability are:

- the decision to keep working
- the flexibility and creativity to make necessary adaptations in the way you do job-related activities or to change the type of work you do
- the willingness to seek the kinds of job accommodations that are available to workers through the ADA

The following are some steps you can take today to maximize your employment options in the years ahead.

STEP 1

REVIEW YOUR CURRENT JOB SITUATION

The best way to begin assessing your current job situation is by looking at the kind of work you do in relation to the type(s) of MS symptoms you are experiencing. If your job is a physical one, you might be particularly concerned about symptoms such as fatigue or problems with walking or balance that would interfere with your job performance. If, however, you have a desk job that primarily requires a lot

of planning and problem-solving skills, you might be more concerned about changes in your thinking, memory or ability to process information quickly and easily. In other words, some people's jobs are impacted by their MS symptoms much more quickly or directly than other people's jobs — it will largely depend on the ways in which your job responsibilities are affected by your particular symptoms. People whose job performance is consistently altered from the outset will need to begin thinking about accommodations or changes sooner than those whose symptoms do not interfere with job performance.

STEP 2

REVIEW YOUR BENEFITS

If you have not done so already, now is the time to familiarize yourself with the benefits to which you are entitled at your current job. Many people take a job without looking carefully at the benefits information, or look only at the health benefits part of the package. If you cannot find the packet of information you were given as a new employee, ask the human resources department or personnel office to send you a new copy. Since this is a routine request made by many employees, you do not need to worry that asking for this information will alert the company to your MS diagnosis. If you are married, you should do a similar review of your spouse's benefits in

order to familiarize yourself with all your options. In reviewing your benefits, consider the following:

- How much sick leave do you have? How do you acquire it, and what are the rules for taking it? Does the company have a pooled or donated sick leave policy whereby your co-workers can turn over unused sick days to you?
- Do you have a short-term disability policy? How is “short-term disability” defined in your policy? How does the policy work? How long a period of time does it cover? Is your current job guaranteed upon your return? Is a medical certification required in order for you to return to work? Do you get paid during this leave time and, if so, how much? Does your spouse have a policy in case he or she acquires a disability?
- Do you have a long-term disability policy? How is “long-term disability” defined by your company? The term “disability” is defined differently by different policies, and many long-term policies are for a five-year period and not for the rest of your life. Are you permitted to supplement or improve your policy? Does your spouse have a long-term disability policy?
- Is your employer covered under the Family and Medical Leave Act (FMLA), which allows employees

of a company with 50 or more employees to request up to 12 weeks per year of unpaid medical leave because of their own serious medical condition or that of a family member? For more information on the Family Medical Leave Act, check with your human resources department or personnel office, or visit the Department of Labor website at dol.gov/whd/fmla.

- Does your employer provide benefits for continuing education or retraining?
- Is your employer exempt from ADA laws? While employers are encouraged to follow ADA regulations, those with fewer than 15 employees are not required to do so. In some instances, however, local regulations may offer protections similar to those of the ADA. If you are employed by the federal government, your agency would most likely follow the Rehabilitation Act of 1973, rather than the ADA.

The answers to these questions will help you plan how to get through an exacerbation or a change in symptoms while continuing with the same employer. If you do not fully understand each benefit after you have reviewed the materials, schedule an appointment with your company’s benefits manager and ask for a full explanation.

Unfortunately, many people leave the workplace during a flare-up of symptoms and later, when the symptoms have gone away or become more manageable, wish that they could return to work. They are faced with the need to find new employment and perhaps a new source of health insurance, or to find meaning and satisfaction (not to mention income) as an unemployed person. By fully utilizing your company's benefits, you will give yourself more time to make an informed decision.

STEP
3

DECIDING TO DISCLOSE

By the time you read this chapter of **Knowledge Is Power**, you may already have told your employer or co-workers about your diagnosis. Some people who have missed many days of work or spent considerable time looking for an explanation of their strange and puzzling symptoms choose to share the new-found diagnosis as soon as possible with colleagues and friends at work. If you have not already disclosed, however, it is well worth your while to take some time to consider the possible benefits and consequences of making your diagnosis public. Once you have given out the information, you cannot take it back.

Potential benefits of disclosure

- You may get additional support from your employer and colleagues once they have a better understanding of what you have been experiencing.
- Having disclosed that you have a disability, you can also begin to make job accommodation requests to improve your performance or make your job a bit easier to handle.

Potential drawbacks of disclosure

- Co-workers and employers may have stereotypes about disability that they will not share with you. For example, they may assume that you will be unable to “hold your own” on the job, thereby forcing them to do more work or causing them to lose money. They may also be concerned that you will “leave them in the lurch” by quitting or being absent frequently.
- Your employer may assume that you will not want further training or promotions or that you will need special treatment or equipment.
- You may find that people react to you differently, focusing on your health status rather than your talents and abilities. Given the variability and unpredictability of MS symptoms from one day to

another, you may even find that people question your disability or wonder why you have some difficulty even on days when “you look so good.”

“Am I required to tell my employer that I have MS?”

If you have no visible symptoms at the present time, and no current need to ask for specific job accommodations, it may be wiser to postpone your disclosure. When, and if, the time comes in the future that you need to request an accommodation, it is important to plan your approach carefully. Although you are not legally required to disclose your medical diagnosis immediately, in some instances it may be in your best interest to do so. Whether or not you choose to say that you have MS, however, you must disclose that you have a disability in order to obtain protections under the ADA and to request accommodations. You need to be prepared to describe symptoms that you are experiencing and the impact they are having on major life activities, including your ability to perform your job. You can also propose accommodations that would be helpful to you in order to perform your job duties. Be aware that your employer may request additional information or

documentation at that time, such as a doctor’s letter certifying the nature of your disability (e.g., fatigue, visual difficulties, problems with walking).

On the other hand, if you currently have visible symptoms that might be confusing to others, or could be misinterpreted as alcohol or drug abuse (e.g., an unsteady gait, balance problems, or slurred speech), you might choose to let others know your diagnosis even if you do not need any special accommodations at this time.

When you begin to disclose, determine who needs to know — is it your immediate supervisor or someone in the human resources or personnel department? As much as possible, you should be the one in control of what information is shared, with whom, and when.

Disclosing your MS — whenever you decide to do it — will require a lot of public education on your part. Be prepared to explain about the visible and invisible symptoms of the disease, and the ways in which they can come and go in an unpredictable way. The National MS Society has several resources that can help you explain the disease to others. Since most people have learned to think of an illness as something that gets better once it is treated, many will have difficulty understanding the ups and downs of a chronic disease.

To help you think through your decisions around disclosure in the workplace, the Society offers a disclosure worksheet at nationalMSSociety.org/DisclosureDecisions or is included in the back of this KIP book if you received it by mail.

**STEP
4**

**CONSIDER
ACCOMMODATIONS**

According to the ADA, the employee must initiate any requests for job accommodations. It is not your employer's responsibility to identify your needs or offer solutions. Therefore, you should review the quality and quantity of your own work before your employer does. Don't wait for a scheduled performance review, and don't wait until you are already in a crisis situation.

Take the time to think about whether there are changes or accommodations that would support your efforts to perform at peak level (e.g., a handicapped parking space, a desk closer to the bathroom, adaptive office equipment, flex-time, etc.). Having identified possible accommodations, present your request to your employer, explaining how these accommodations could enhance your work efforts. The National MS Society has published a booklet entitled, **The Win-Win Approach to Reasonable Accommodations** that can guide your

efforts to identify and request possible job accommodations.

After the accommodation request is made, the law states that the employee and the employer share responsibility for planning the specific accommodations. It would be in your best interest to do some advance research and planning so that you can present some options to your employer at the time of your request.

If you do not know about the types of accommodations that are possible, contact the Job Accommodation Network (JAN) 1-800-526-7234 to discuss your symptoms and work requirements, or go to their website at askjan.org.

“I want to be as productive as I can be on my job. Who can help me figure out how to do that?”

An occupational therapist (OT) can also be a valuable resource in your efforts to identify appropriate accommodations. Following an evaluation of your work environment and job functions, the OT will suggest strategies and tools for improving

your job performance. With these suggestions in mind, you will feel more prepared to present your requests to your employer. Your neurologist may be able to refer you to an OT with experience working with people with MS. Also, contact the National MS Society to receive OT referrals.

STEP 5

LOOK INTO FURTHER TRAINING

The next step is to ensure that you are optimally trained for your present job. By taking advantage of any employer-sponsored education or training opportunities, you will demonstrate your commitment to your work, keeping yourself current in your field, and giving the message that you are ready for the next career step in the company.

STEP 6

PLAN FOR THE FUTURE

At the same time that you are working to update your present skills, start to think about your next career move. This is particularly important if your current job requires a lot of physical activity that may be compromised by a change or worsening of your symptoms, or if you are concerned that any of your symptoms may someday prevent you from doing your current job. Changing careers is not unusual in this day and age. Career counselors

report that many Americans change careers several times in their working life. A vocational rehabilitation specialist or career counselor can help you identify possible career options, as well as the programs and payment plans that are available to help you pursue your goals. The National MS Society can help you locate a vocational specialist or career counselor in your area.

STEP 7

IDENTIFYING WAYS TO MANAGE STRESS

Coping with a chronic illness and identifying ways to manage the demands of work in the face of variable and unpredictable symptoms can be highly stressful. Many people diagnosed with MS believe they should stop working in order to minimize any stresses that might hasten disease progression.

Since research has been unable to confirm a clear link between stress and either the onset or worsening of MS symptoms, and since modern-day life is filled with stress whether one is working or not, the more reasonable course is probably to continue working as long as you find it necessary and/or satisfying to do so. After all, finding yourself without the economic, social and emotional benefits of employment can also be highly stressful.

Perhaps the more reasonable approach is to review your usual stress management techniques and invite family members to do the same. Maybe you've never thought about how you manage stress. Many people take breaks from their everyday pressures and tensions by engaging in hobbies, sports activities or simple distractions like TV or music. This strategy can be effective as long as your chosen activities are not affected by your MS symptoms. If, however, you can no longer find the same relaxation or enjoyment because your symptoms are getting in the way, now is a good time to explore new options for stress management. For example, people who have always used competitive sports as a way to relax and "blow off steam" may be frustrated by their inability to play as well as they used to. They may be uncomfortable with the temporary worsening of symptoms that can result when they get overheated. Swimming, water aerobics, yoga or T'ai Chi may be satisfying substitutes.

Other stress management techniques you may want to explore include meditation, art projects or music. A counselor or recreation therapist can help you explore options that match your interests, abilities and life situation. The important point is that stress is so much a part of our daily lives that efforts to avoid it can never be successful.

“Sometimes work is so stressful I’m tempted to give it all up, but I know that being out of work would bring its own set of stresses.”

People who try to avoid stress by gradually removing themselves from any and all situations that are challenging or difficult find that life has lost much of its interest and satisfaction. And this becomes a stress all its own.

**STEP
8**

**USE AVAILABLE RESOURCES
AND SUPPORTS**

This crucial step could as easily be the first step as the last. Employment decisions and career planning are not simple, and there is no need for any individual to "go it alone." Vocational counselors, career counselors, mental health professionals, a peer with MS or a supportive mentor can all provide helpful information and guidance as you work to explore and maximize your employment options. In addition, there is now a field of disability law that can help people understand their

rights and responsibilities under the ADA. The National MS Society can provide you with employment-related educational materials as well as referrals to a variety of specialists in your area. Try to make use of all the available resources and keep up the good work.

Optimizing your financial future

One hallmark of MS is its unpredictability — one person's future with this disease may be very different from another person's. Effective financial planning starts with recognition of this unpredictability so that you can take steps to protect yourself and your family in the face of whatever changes might occur.

You can start by taking a careful inventory of your income and expenses. You might also want to go to **annualcreditreport.com** to request a credit report from one of the three agencies that report credit ratings — Equifax, Experian or TransUnion. Once you have a clear picture of where you stand today, you can begin to think about the way this picture might change in the future because of MS or other events in your life.

- Potential changes in income might occur for many reasons, including career advancement, job change or

loss of employment; progression of MS symptoms; change in marital status; change in spouse or partner's income; inheritance; fluctuations in investments, and so on.

- Potential changes in expenses might occur because of increasing medical costs; changes in insurance coverage; a change in living situation; starting a family or adding to your family, anticipated college expenses, among other things.

Many people find it stressful to think about their finances, even under the best of circumstances. In the face of a new MS diagnosis, the thought of planning for your financial future may seem particularly stressful. However, it is to your advantage to begin now so that you can feel more prepared — and more secure — no matter what the future brings. Keep in mind that you do not have to do this on your own; there are many professionals with the expertise to help you with this process:

- **Accountant** — Your personal accountant is the best resource for information about how to make best use of your assets, invest for an unpredictable future and take advantage of available deductions on your taxes.
- **Financial Planner** — A certified financial planner can help you set goals for your financial future and take steps to meet them. Call the Society (1-800-344-4867) for

information about the free financial consultations offered through Financial Education Partners.

- **Attorneys-at-Law**
 - » **Elder Law** — These lawyers specialize in the needs of the elderly and people living with disabilities. They can provide information and guidance around Medicare and Medicaid benefits, wills and trusts, and financial planning for potential long-term care needs. You can find an elder law attorney in your area by going to nelf.org/find-a-cela.
 - » **Social Security** — Assists people with applications for Social Security Disability Insurance and Supplemental Security Income, as well as appeals. The National Organization of Social Security Claimant Representatives (NOSSCRO) is your best source for a referral. Visit nosscr.org/helping-you/referral-service or call 800-431-2801.
- **Credit Counselors** — The National Foundation for Credit Counseling assists people who need help reducing unmanageable debt. Call 1-800-388-2227 to find a credit counselor in your area.

By taking steps today to manage your finances in the most effective way, you are creating the safety nets you need to feel more secure in the face of an unpredictable chronic illness.

Things to think about

- You can continue to work for as long as you are interested and able.
- Becoming educated about your company's benefits and your rights and responsibilities under the ADA will help you maximize your options and prepare for the decisions ahead. Recommended websites to explore include:
 - » **U.S. Department of Labor Office of Disability Employment Policy**
dol.gov (866-633-7365)
 - » **U.S. Equal Employment Opportunity Commission**
eeoc.gov (800-669-4000)
 - » **U.S. Department of Justice ADA**
ada.gov (800-514-0301)
 - » **Social Security Administration Office of Employment Support**
ssa.gov/work (800-772-1213)
 - » **National Organization on Disability**
nod.org (202-293-5960)
- Become more familiar with the ADA and accommodation strategies that may be helpful to you. Contact the Job Accommodation Network (JAN) at 1-800-526-7234 or visit them online at askjan.org. Learn more about the ADA Technical Assistance Program at ada.gov.

- Take responsibility for your own job performance; don't wait for your employer to do it for you. It is your responsibility to identify and request the accommodations you need to function at an optimal level.
- Be proactive. Don't wait until you are already in a crisis situation to take action. Once your job performance is under review, it can be far more difficult to ask for, and be given, the necessary accommodations.
- When you begin to disclose, determine who needs to know. Is it your immediate supervisor or someone in the human resources or personnel department? As much as possible, you should be the one in control of what information is shared, with whom, and when.
- Learning to manage life's stresses is far more effective and satisfying in the long run than trying to avoid them.
- Sound financial planning today can help you feel more prepared for the unpredictability of the future.
- Use the available resources to help you; there is no need to "go it alone."

Resources

Thousands of resources, pieces of information and shared experiences about MS are available in print and on the internet. Some of the information you come across may be strictly experiential, anecdotal, unsupported or even inaccurate. Always consider the source; ask your healthcare provider or the National MS Society to help you identify credible resources.

From the National MS Society

For answers to questions about employment, benefits and health insurance concerns, contact the National MS Society at 1-800-344-4867 or visit nationalMSSociety.org or the following topic-specific pages:

- nationalMSSociety.org/employment
- nationalMSSociety.org/KIPworkandmoney
- nationalMSSociety.org/disclosuredecisions
- nationalMSSociety.org/SSDI (Social Security Disability Insurance)
- nationalMSSociety.org/planning — life planning and independence

- **nationalMSSociety.org/modifications** — home and work
- **nationalMSSociety.org/financialplanning**
- **nationalMSSociety.org/financeguide** — 72-page financial planning workbook, **Adapting: Financial Planning for a Life with Multiple Sclerosis**

The Society produces many other resources about various aspects of MS. These resources are available online or call 1-800-344-4867 to request.

- **nationalMSSociety.org/educationalvideos**
(also at youtube.com/nationalMSSociety)
- **nationalMSSociety.org/brochures**
(or see the Catalog of Informational Resources mailed with this book if you received it by mail)

Books

Books may be available at bookstores and/or online booksellers.

- Murray T J, Saunders C, Holland N. **Multiple Sclerosis: A Guide for the Newly Diagnosed** (2012). (NY:DemosHealth)
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have; The Answers You Need** (5th ed.) (2012). (NY:DemosHealth)
- Rumrill PD, Hennessey JL, Nissen SW. **Employment Issues and Multiple Sclerosis** (2nd ed.) (2008). (NY:DemosHealth)

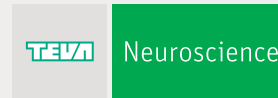
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The National MS Society’s mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.

The National Multiple Sclerosis Society (“Society”) is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient’s use of any product or service mentioned. The Society does not independently verify whether the information provided by each service provider is accurate. The Society undertakes no responsibility to verify whether the service provider is appropriately licensed and certified and has applicable insurance coverage.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **nationalMSsociety.org** or 1-800-344-4867.



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1-800-344-4867