WHY DO WE WORK?

All of us work for many reasons. Certainly, bringing home income is critical, as is the security of having employer-paid health insurance. Perhaps less obvious is the sense of purpose that comes with working. Work can be an important part of your identity. In the workplace, you have the opportunity to demonstrate your skills and to experience recognition for your competence and to achieve success. Finally, your workplace provides you with opportunities for positive social interactions. As you most likely know, when you have multiple sclerosis (MS), issues around work may become complicated.

When you have MS, working can have costs as well as benefits. For example, work can be very tiring. You can get so tired during the workday that when you get home from work, you have no energy left for leisure or even for necessary activities such as shopping. Some people living with MS find that they must choose between working and having a good quality of life after work.

Also, work can be stressful, particularly if you are experiencing cognitive changes, fatigue, or pain. When you have cognitive changes such as difficulty with memory and multitasking, it takes energy and focus to think effectively and efficiently. You may have to become more vigilant to make sure that you say what you want to say. For some, this extra effort leads to greater fatigue, which promotes further difficulty in thinking. When you experience a combination of some of these factors, interactions with your coworkers and supervisors may become quite stressful.

On the other hand, being unemployed, not having health insurance, and being home alone also can be very stressful. As one person in our qualitative research study noted,
I don’t think about being tired when I’m at work—my mind is too busy to think about my legs hurting. That’s the best reason why people should work. You forget about the MS. If I am home, I get really depressed.

So, you have to balance the costs and the benefits you experience by working and then you will be in a better position to make a decision about employment that works for you and your family.

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**BARRIERS TO WORKING**

So let’s assume that you’ve decided either to continue working or to reenter the workplace. What are the barriers that you may encounter? And what kind of strategies can you use to address these barriers? First of all, let’s not underestimate how significant these barriers may be. Given their educational level and age, people with MS are unemployed at a much higher rate than would be expected (Law and Noyes 2005). Since about 70 percent of those with MS are women, and they are usually diagnosed in their twenties (Kurtzke 2005), some of this unemployment may be due to the fact that some women may have been out of the labor market during their childbearing years. However, from the research, it looks as though people with MS leave the labor market prematurely (Fraser, McMahon, and Danczyk-Hawley 2003). Moreover, in surveys of people with MS, many who are unemployed say they wish they could have a job, and those who continue to work place a high value on their employment (LaRocca and Hall 1990; LaRocca et al. 1985). So we will begin by looking at employment barriers that are related to having MS, and later we will look at barriers to employment that are related to society or to the work environment.

**Fatigue**

Fatigue can come in many different forms. Sometimes, you may wake up in the morning and be so dead tired that you can’t even begin to think about going to work; that kind of fatigue can continue for several days. Often, this kind of fatigue is associated with an exacerbation of MS. So, if you experience this kind of fatigue periodically, when you address accommodations for fatigue in your workplace, it will be important for your physician to document that this is not just about being tired. Significant fatigue associated with your MS is a legitimate reason for you to miss work. When you are this tired, most likely it isn’t even feasible for you to try to work from home until your energy picks up again.

More frequently, though, you may find that you experience more fatigue as your workday progresses. For this kind of fatigue, it will be helpful if you can figure out a pattern. For example, if you know that you usually have more energy in the morning, you may be able to schedule important activities earlier in the day. Also, you might notice that you get really tired around lunchtime, in which case, as a reasonable accommodation, you might request that you be allowed to combine your lunch break with your afternoon break so you can take a nap. Some clients in our employment programs set a timer and nap in their car, or they use a cot or floor mat for rest, or they actually go home for a couple of hours of sleep, returning for the late afternoon shift (e.g., 3:30–6:30 P.M.). Other clients refresh themselves with a timed fifteen-minute nap in the afternoon.

Some people have had great success learning and using relaxation techniques, such as progressive muscle relaxation, meditation, or meditative prayer. They find that deep relaxation for ten or fifteen minutes, two or three times during the day “recharges their batteries.” And, as one individual explained, “MS fatigue is different. When those of us with MS use the word ‘fatigue,’ you might think ‘tired,’ but it’s
different. Our reserves are depleted and they don’t refill; you can’t refill them.” Finally, some medications, such as amantadine or provigil, have proved effective for some people with MS in combating fatigue. You can discuss their use with your physician.

**Cognitive Changes**

Cognitive changes in the workplace can be very tough and may require strategic thinking to accommodate. Cognitive changes might include difficulties with memory, paying attention to tasks, and problem solving (particularly under pressure). There also may be problems with thinking more slowly, having difficulty finding words, or having difficulty with multitasking. As one person described it, “There are cognitive problems. I don’t think as clearly as I used to. That doesn’t mean I can’t do my job, but it is more of a struggle.”

Managing fatigue and heat sensitivity will be important because you may have more difficulty with cognitive tasks when you are too hot or more tired. If you can, schedule your more demanding activities for morning hours. One woman with MS goes to work two hours before her coworkers arrive so she can concentrate on complex financial tasks, without the distractions of coworkers’ voices and telephones ringing, and so forth. She schedules less demanding tasks for afternoons when she is less efficient cognitively. Additionally, she tries to schedule her phone calls for an hour in the early afternoon so she can focus on one function at a time. When she gets home, she routinely takes a nap, so by the time her husband gets home from his job, she is rested enough to enjoy some quality time with him.

**Three Rules to Help with Cognitive Changes**

The primary rule in accommodating your cognitive changes is routine, routine, routine! The idea behind insisting on routines to follow is that the more activities that are predictable, routine, simple, and automatic, the more physical or cognitive energy you will have available to apply to higher-level activities.

This primary rule begins with what may seem simple, but for many of us is difficult: unclutter your workspace. Removing distractions by making sure that unnecessary papers and objects are filed away (or discarded) will help you to work much more efficiently. Also, it can be very helpful to have a daily reminder system with a to-do list and a good filing system so that you can schedule time to remember what’s the next item on your work list.

Let’s look at an example of the cluttered desk. Shown below are two photos of a “before and after” intervention that was done for a woman having difficulties attending to her tasks at her workstation. Although this was a relatively simple intervention, the difference it makes in her ability to get her job done is obvious.

The second rule might be repetition, repetition, repetition! When you find it more difficult to learn new material, or to understand complex material, repetition may help. One woman with MS said that when she was younger, she would quickly scan complex reports before meetings with clients and retain enough information to hold her own. Now that she has some cognitive problems, she reads the reports the evening before her meeting, highlights relevant sections with a highlighting pen, and then scans the highlights the next day just before the meeting. This takes her about twice as long, but it allows her to be well prepared and effective during her client meetings. Other people with MS tape-record highlighted material for themselves and review the audiotape several times before key meetings.
Figure 8.1: This “before” photo shows the cluttered work space of a woman with MS. She asked for assistance because it was difficult for her to focus on her work.

Figure 8.2: In this “after” photo, the work space has been redesigned to be more efficient. Notice that all materials are organized and the clutter is gone. A flat-panel computer monitor has replaced the old monitor, freeing up desk space. A new desk was provided that allows her to easily move from activity to activity in her wheelchair.
The third rule might be organize, organize, organize! Think about the scope and flow of your work. What kinds of things do you need to remember? What kind of strategy will work best for you personally? For some people a daily planner is just the ticket. You can use it as your memory book. Not only can you write down all your appointments, you also can take notes in the Notes section, maintain a to-do list, and have references to important notes or tasks in your calendar. You can find different organizing systems at most office or business supply stores. Speech and language pathologists knowledgeable about memory can also help design customized tools and strategies.

Electronic Devices

What about electronic devices? Anything that you do with a daily planner, you can certainly do with a personal digital assistant (PDA) running either the Palm OS® or the Pocket PC®. The advantages of these systems are that they have alarms that can be set to remind you to check them and they have multilayered, sophisticated organizing systems such as Microsoft Outlook®. The disadvantage of PDAs is that it may be difficult to learn to use them if you are not comfortable with the technology. Also, you must make sure the battery is charged and data are backed up.

Some people with MS set up their desktop computers to help them work more efficiently. For example, using Microsoft Outlook®, they have set up their e-mail so that it sorts messages into logical boxes, making it easier to see what needs to be attended to quickly. One woman showed me how she had used color coding. For the same reasons that were discussed regarding your work space, you should make sure that the desktop on your computer is organized and uncluttered.

Many people with MS have told the author that they use e-mail as a memory aid. They e-mail messages to themselves so they can remember to update their calendars and their to-do lists. You can also use a text pager or a cell phone as a memory aid. Your computer can send text messages from the schedule in Outlook to your cell phone or to your text pager, reminding you of important activities. A low-tech version is used simply to call your home or cell telephone message service and leave yourself reminders.

Depression

As described in chapter 5, depression is common among people with MS. And, as you can imagine, because of the relationship between depression, fatigue, and pain, depression can be quite a barrier to employment. Therefore, if you have any concerns about depression, I recommend that you review chapter 5 and seek treatment from someone knowledgeable about both depression and MS.

Pain

In the research literature, between 44 to 80 percent of those with MS report that they have pain (Ehde, Osborne, and Jensen 2005). Because pain can be intrusive and increase fatigue, it will be important to minimize the impact of pain at work, and in your life in general. This may require medical intervention and, perhaps, managing your activity patterns. Obviously, the medical intervention route requires a trip to your healthcare provider and a description of the pain that you feel. Managing your activity patterns may include taking strategic breaks at work, ensuring that you are as rested as you can be, and taking time-outs so you can use cognitive strategies to help disrupt your pain.
Heat Sensitivity

Approximately 80 percent of people with MS report some kind of heat sensitivity (Halper 2005). They say that mostly they don’t do as well when they are too warm as they do when they are cool. Occasionally, some people with MS are sensitive to cold. In the workplace, a request that you be provided with control over the temperature in your work area would be a very reasonable accommodation. In warmer climates or seasons, limiting your trips outdoors during the hotter part of the day is sensible. Air-conditioning for your car during commutes can be critical.

It also may be beneficial in general to carry a thermos of iced water with you in warm weather. In some cases, a simple, portable air-conditioner in the work area is sufficient. If you are extremely sensitive to heat, a cooling jacket or a heat-extraction system may really boost your tolerance for work. Cooling jackets are unobtrusive garments worn by people with MS, they provide a personal cooling system. Your physician will be able to review your options. Heat-extraction systems are worn on the body as vests or jackets and are either pre-cooled or attached to portable devices that cool continuously.

Mobility

You may be one of those with MS who experience difficulty with mobility. Some people find that they tire very quickly when walking. Others are unsteady, have difficulty walking, and some are unable to walk. To address limitations in mobility, you can use basic mobility aids such as canes, walkers, or wheelchairs. Difficulty with mobility can have an impact on work from many different perspectives. Getting to and from work may take more time and effort. Traveling distances while at your work site may take more energy and time. Some jobs require that employees travel off the worksite, or even out of town, and mobility limitations can pose significant challenges in this area.

Finally, nonwork activities can come into play. If walking is tiring or difficult, activities such as shopping for food may take much more energy and planning, depleting energy stores for the next workday. If you find this to be true, you may want to conserve your energy by shopping online or by using the phone for groceries and other items, and having them delivered to your home. Or a friend or volunteer might pick up your packages for you. Making quarterly bulk purchases for staples and frozen food items at low-cost grocery outlets and warehouses can save you time and money.

For people who tire easily when walking, there are a couple of potential accommodations that may help. First, it may be possible to move your office or desk to reduce the walking distance to the restroom, cafeteria, or parking area. One woman told me she was able to reduce her walking by 50 percent simply by switching offices with a coworker. Mobility aids, such as modified walkers with seats, can help you feel more stable and give you a place to sit and rest on this while waiting for a bus, and then fold it up to board the bus.
to sit and rest periodically. The range of options includes the use of various power mobility aids, including scooters and power wheelchairs. These can be used not only at work but in all environments.

One woman told me that she was becoming very fatigued from the walking she had to do while at work. She applied for services with the state Department of Vocational Rehabilitation for assistance in maintaining her employment. They provided her with an evaluation of her mobility needs at work and, as a result, purchased a power wheelchair for her to use.

She decided to use the power wheelchair only at work because it would have been very expensive for her to buy a van to transport the chair, and it was not convenient for her to use public transportation in the power wheelchair. Also, her apartment was small and would not have accommodated a wheelchair easily. Her employer moved her to a larger office, and the building owner built a locking cabinet in the parking garage where she can leave her wheelchair when she isn’t at work.

She said that this solution reduced her fatigue and pain significantly, and she discovered that she now can join her colleagues when they lunch at restaurants in the neighborhood. The wheelchair increased her ability to engage with others both in her occupation and in her social life.
**Bladder and Bowel Difficulties**

Bladder dysfunction is one of the top five most prominent symptoms affecting the quality of life for people with MS (Rothwell et al. 1997). Nevertheless, if you have experienced persistent bowel and bladder difficulties, understandably you find these very distressing, even imprisoning. The causes of bladder and bowel problems vary with disease function, as do interventions which can range from managing fluid intake and caution with diet, to use of a condom, intermittent or indwelling catheters, medications, or, occasionally, surgery. If you are having bladder or bowel problems, consult your healthcare provider right away and, if necessary, ask for a referral to a specialist such as a urologist familiar with neurological disability who can help you devise a management strategy that will limit the interference at work and in your community.

**SOCIAL, PROGRAMMATIC, AND ENVIRONMENTAL BARRIERS**

It's clear from the research about disability in general, and MS in particular, that many of the barriers to employment are not related to the functional limitations you can experience as someone with MS; rather they are related to social attitudes, policy issues like healthcare insurance benefits, and environmental variables such as temperature and curb cuts. These barriers can be difficult to detect and can be powerfully disabling, so it is important that you consider them carefully.

**Social Barriers**

When you encounter problems related to MS at work, it's natural that your family and healthcare provider may suggest that you should quit your job. You, however, may very well continue working with the appropriate accommodations. The economic and social consequences of unemployment may be more stressful than working. So, it's important to recognize that the suggestions you receive are just that—suggestions. They reflect the attitudes of those around you, without consideration of the complex issues you are facing. Be especially cautious about making decisions about employment during an exacerbation. First, let matters stabilize, and then take your time to make the decision that will be best for you. Consider the advice you're getting from those around you, but also think about using the planning process we describe below to make sure you take into consideration all of your areas of concern.

Assuming the people in your workplace know you have MS (there will be more about disclosure later in this chapter), your employer or coworkers may over- or underestimate the degree of your level of disability. They may believe that because you have difficulty speaking clearly or walking steadily when you are fatigued, that you are cognitively impaired. What's more, they may not share that perception with you and then make decisions about the tasks that are assigned to you or the promotions you receive based on their incorrect perceptions. These attitudes and beliefs can result in discrimination and have a negative impact on your work. As one woman with MS put it, “I think basically you get stereotyped and they see you as your ailment and they don’t see you for yourself.”

There are a variety of ways to confront attitudinal barriers. You may choose not to disclose that you have MS in the workplace. You may try educating your coworkers or employers during a relaxed period in the workday (e.g., at a break or at lunchtime). Since the passage of the Americans with Disabilities Act (ADA) of 1990, discrimination in employment against people with disabilities (which affect one or more
Programmatic Barriers

Programmatic barriers to employment can be formidable. You may feel that you can’t change jobs because that would require you to change your healthcare insurance, and a new policy would exclude MS treatment as a preexisting condition (see chapter 9 for full discussion of this issue). Also, you may feel that you must quit work because you need governmental healthcare coverage, such as Medicare or Medicaid, to pay for your medical care and medications. Perhaps you’ve discovered that the special medications you take for your MS are covered under your major medical coverage rather than your prescription drug coverage, thus requiring a big outlay of cash from you every month. The lack of universal health care coverage in the U.S., and the absence of consistency in employer-funded healthcare coverage plans can put those who have MS into very difficult positions with respect to employment.

Furthermore, there are other kinds of programmatic issues you may have to face. For example, is there a good public transportation system in your area? If so, is it fully accessible to people with disabilities? Does the local governmental office of civil rights consider disability issues to be a priority? Are services available from the state Department of Vocational Rehabilitation? Is there an interdisciplinary team associated with your healthcare provider who can help you identify appropriate accommodations? If not, you may want to seek a consultation through a more comprehensive MS center.

Environmental Barriers

Finally, let’s consider environmental barriers. Climate can be a big environmental barrier for people with heat sensitivity. Would you function better in Miami, Florida, or Seattle, Washington, in the summer? Climate can also be a big barrier for people who have difficulty with mobility. Would you rather navigate the winter snow in Buffalo, New York, or the rain of Eugene, Oregon? And what about terrain? Would you rather climb (on foot or with your mobility device) the hills of San Francisco or the level streets with bike lanes in Davis, California? And what about elevators and curb cuts? Can you travel from where you live to work and to key points in your community without experiencing obstructions?

Unfortunately, despite the legal requirements of the Americans with Disabilities Act, some communities remain relatively inaccessible to people with disabilities. One of our clients recently sold a home in Seattle to winter in Florida and live with family in a Long Island beach town in the summer, both for the climate and support needs. Moving to a more disability-friendly or accessible community might be a realistic option for your consideration.

DEVELOPING YOUR PERSONAL ACCOMMODATION PLAN

Now, let’s put this all together and discuss your personal accommodation plan. After reviewing the barriers and potential solutions described in this chapter, turn to the back of this book, and take some time to carefully review the Work Experience Survey (Roessler and Gottcent 1994) in appendix A. You
will then be in a better position to make a few important decisions: Is it in your best interests to continue working (or get a job)? Should you disclose to your employer that you have MS? What kinds of accommodations would be useful to you at work and who should pay for them?

Dr. Roessler recommends that sections II–V of the Work Experience Survey (see appendix A) can be used, more easily, to better clarify your barriers to employment, potential solutions, and the “who” and “how” of each solution. You can also take the results of your efforts and seek assistance from a rehabilitation counselor, a speech and language pathologist (familiar with neurological and cognitive rehabilitation), a rehabilitation counselor or neuropsychologist, an assistive technology specialist, or other professional recommended by your healthcare provider, state vocational rehabilitation agency, or local MS organization.

There are also a number of resources available on the Web. For example, you can learn more about your legal rights from the Department of Justice Web site (see Resources). Information about how to accommodate your job barriers can be found at the Job Accommodation Network (JAN) and information about useful equipment or assistive technology can be found at ABLEDATA (see Resources section at the end of the book). Using JAN as an example, you pose your barrier and accommodation question on the Web site and, usually, you will receive a recommendation for accommodation by e-mail within a day. Options can include the manner in which certain companies make accommodations, the offerings of the manufacturers of assistive technologies or adaptive software, and even journal articles comparing the benefits of different accommodation strategies. Having worked through this process, you will then be better prepared to discuss your needs with your current or prospective employer.

It’s important to think through how the potential accommodation costs will be covered: By your employer? By you? By a state vocational rehabilitation agency? By some combination? Fortunately, most accommodations are inexpensive, costing less than $500. Often, the accommodation needed is simply a procedural change (e.g., modifying your work schedule versus physical modification to the workstation itself).

**DISCLOSING TO YOUR EMPLOYER**

So, now let’s presume you have decided to keep working or to get a job, and that accommodations would be useful on the job. Should you tell your employer that you have MS? For some people, it may be difficult not to disclose since others can see they have a disability of some kind because they use a wheelchair, have difficulty with speech, and so on. But for others, MS may be an “invisible” disability, and the decision to disclose is up to the individual.

You may choose not to specifically reference multiple sclerosis, but simply disclose that you have a disability that affects you in certain ways and requires certain accommodation. This is your call and you may want to discuss this with your physician, spouse, and significant others.

On the other hand, disclosing to the employer is necessary to establish your legal rights. And, from a practical perspective, it may be difficult to negotiate even small accommodations, such as modified breaks to allow brief naps, without explaining why they are needed.

Usually, disclosure to an employer is appropriate only when you are making a request for a “reasonable accommodation.” Under the ADA, and many state laws, if you are a “qualified individual with a disability” (your MS affects “one or more major life areas”), and you can perform the “essential functions of your job” (that would be the functions that are clearly central to your job), “with or without accommodation,” and your employer is a “covered entity” (under federal law, the company is a “covered entity” if your employer has twenty-five or more employees; and under some state laws, the company is a
covered entity if your employer has as few as eight employees), your employer is required to pay for “reasonable accommodations” necessary for you to do your job, and cannot discriminate against you because of your disability. “Reasonable” is not defined, but is based on administrative regulations and case law. What is reasonable depends on the size of the employer, the amount of revenue, and other factors. The “reasonable accommodation” cannot impose an “undue hardship” on the employer. Unfortunately, if you have MS and are in remission or have fewer symptoms than most people with MS, you may not be covered under ADA, although you may be covered under state law.

So, to whom do you make your request for accommodation? With larger employers, that request is usually made to the Human Resources department. Some larger companies will have a Disability Services Unit with vocational rehabilitation counselors on the staff. Under the law, you are not required to disclose that you have MS, but you must state that you have a disability, and you must state the functional limitations you want to address with the accommodations. Your employer has the right to request verification of your functional limitations from your physician, but you have the right to ask your physician to document the limitations but not to include the diagnosis.

For example, you could ask your physician to verify that you have significant fatigue that is unpredictable and you need flexibility in your schedule to accommodate your fatigue; and that with that accommodation, you can do your job, but if you choose not to mention MS, you don’t have to. There are no right or wrong answers here. The decisions about whether to disclose and what to disclose are very personal. You may find that you feel more comfortable telling your supervisor and coworkers, or you may cherish your privacy. Again, you may decide to find your own accommodations. Of course, making different decisions will have different consequences.

Worksheet 17 below reviews your decision-making process. Note that if you decide not to work and to pursue Social Security Disability Income, medical retirement, and so forth, you may be able to do some part-time work (based on your capacity for work) that is not considered substantial gainful activity (SGA). This can be reviewed with a vocational rehabilitation counselor or Social Security representative. If you are considering some part-time work, you still will need to consider the disclosure issue. When going through the process, you will need separate sheets of paper for your observations in relation to decision-process points A, B, C, F, and G, H, and I. Information in relation to your limitations and solutions/accommodations can be developed by using the Work Experience Survey you will find in appendix A.

Conclusion

When you have MS, the decision about whether to work can be very complex. Psychological, social, and economic variables all come into play. When you have difficulty with some elements of work because of your MS, accommodations can be very helpful. Often accommodations are simple, inexpensive, and common sense (e.g., using a day planner). At other times, however, such as when you need to reduce your work-related travel or modify a restroom door, you may need to consider disclosing your MS, or at least your fundamental limitations, to your employer. You can then request that the employer pay for or assist with the accommodation, seek accommodation funds from a state vocational rehabilitation agency, or even pay for it yourself if it is not particularly costly and you wish to avoid bureaucratic red tape.
Disclosure Note: See worksheet 15 in chapter 7 for the disclosure script.

A  Review your strengths, preferences, and interests

B  Review financial and insurance issues

C  Consider family needs

E  Describe accommodations

D  Review functional limitations

F  Weigh the costs and benefits to you working, and then decide whether to keep working/get a job, or not work

You've chosen to maintain employment. Now should you disclose?

You decide not to work, but to apply for disability/Social Security subsidy

G  What are your personal feelings about disclosure?

H  What are the social issues in the workplace?

I  Type of employment and legal/economic issues (E.g., who pays for the accommodations?)

Personal decision to disclose MS to your employer or not