

CHAPTER 7

Employment Strategies and Community Resources

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As someone with multiple sclerosis (MS), you face a number of employment challenges within your community with the onset of this disability. Typically, onset occurs sometime in the thirties or forties when you are deeply involved in your career. Consequently, there are a number of immediate concerns that can leap out at you. These concerns can take the form of these questions: “Can I continue to work, particularly in my challenging/stressful field?” “Will I become too fatigued over the workday to continue at my job?” “Can I focus and cognitively complete my major work functions?” “Maybe I should change jobs?” “How should I go about it?” “Should I work part-time and/or consider Social Security Disability Income (SSDI)?” “Maybe I can use the Family Medical Leave Act (FMLA) to reduce my work hours or take time off?” “Could I be self-employed or possibly work at home?” “What resources are available to me in the community?” “In general, what are my options?”

These types of questions can overwhelm you at the time of your initial diagnosis and as you experience the disability and try to adapt to it. In this chapter, the full range of these issues will be addressed.

STAYING ON THE JOB

If you are newly diagnosed and your medications are new or being adjusted, it is important to utilize the Family Medical Leave Act (FMLA). Information from your physician is kept separately from your personnel file and you are not required to disclose your disability to your superior or to your coworkers. The

twelve weeks of permitted time off do not have to be taken in one segment. Furthermore, the actual hours taken from work can be spread out so that you leave work for as few as one to two hours early every day, because that is all you can physically or cognitively handle. Be creative with this time and be sure to contact your company's Personnel/Human Resources or Disability Services department. That department will have specialists on the provisions of the act (FMLA).

Family Medical Leave Act (FMLA)

This act is a federal law that enables you to use up to twelve weeks of nonpaid medical leave over the course of twelve months due to your MS. Again, it can be used all at once, or it can be spread out over a year. Your spouse, biological parent, son, or daughter can also use it to provide for your care and independent living assistance (e.g., shopping, cooking, etc.) while you are receiving treatment. FMLA payments cover both private and publicly held companies with fifty or more workers. You must have been employed for 1,250 hours during the year before you become eligible for this leave. Certain key personnel within companies may be excluded from FMLA coverage. You will again need to check with your company's specialists. For further information, contact your local office of the U.S. Department of Labor. Some states also offer this leave to family members. Check the federal government pages in your phone book for the number of your state's Department of Labor.

Disclosure

If you have a good relationship with your employer, a clear disclosure of your disability with an explanation of your functional limitations can be very important. When you do this disclosure, however, it is critical to research (to the best of your abilities) the best work accommodations specific to your limitations. See chapter 8 for the procedure for examining your accommodation needs and consultation services.

This procedure could involve reviewing the Work Experience Survey (WES developed by Dr. Richard Roessler and colleagues at the Arkansas Rehabilitation Research and Training Center [see appendix A for the survey]). It could also involve spending some time with a rehabilitation counselor or assistive technologist.

Work accommodations can be procedural (a modification of how things are done), involve some structural changes to your workstation or moving your workstation (e.g., closer to a building entrance or to restroom facilities), or the use of some type of assistive technology (e.g., specialized software, such as voice-activated software).

Practice Your Disability Disclosure

You should carefully practice your actual disclosure statement. Your statement should be relatively free of medical jargon, focused on the limitations and specific accommodations that you are seeking, and brief but concise. If you present this information in a clear and positive manner to your employer, he or she will feel a significant amount of reassurance and be inclined to better engage in the process. You do not have to disclose MS, but, basically, you do need to describe "a disability" that presents certain limitations. See the National Multiple Sclerosis Society Web site in the Resources section at the back of

the book for a more detailed discussion of disclosure with practice (e.g., role-play with a friend). Note that role-play can make the disclosure a much easier process to go through.

WORKSHEET 15: DEVELOP YOUR DISCLOSURE SCRIPT

Example

Thanks for meeting with me, Ms. Kindress. I've really enjoyed working here in the accounting department. However, I need to bring to your attention the fact that I now have a disability which causes me to get tired in the early afternoon. (Disclose the actual disability at your discretion.) I feel that I can continue to do my job well if you can make an accommodation in my work hours. Such an accommodation would be in my best interests and that of the company. I would like to come in earlier by an hour and take a two-hour rest in my office between 12 and 2 P.M. In this way, I know I can maintain my proficiency over time and continue to be an asset to the company.

My Script

I need to bring to your attention the fact that I now have a disability which [describe functional limitation] _____

I feel that I can continue to do my job, but an accommodation is in my best interests and that of the company. I would benefit from [describe accommodation] _____

If a local accommodations consultant is needed and one is not available, or the company cannot find technical assistance (as mandated by the Americans with Disabilities Act [ADA]), resources such as West Virginia University's Job Accommodation Network (JAN) can be utilized (see Resources). See also see the material on accommodations in chapter 8.

ASSISTANCE FROM A STATE VOCATIONAL REHABILITATION AGENCY

Every state in the United States has a state vocational rehabilitation agency that is funded by a federal-state dollar match. Usually, as a person with MS, you will fit the level one category of eligibility under an *order of selection* based upon MS being considered a severe disability. This will all be explained to you when you visit your local agency (found in the phone book's state agency listings) during orientation to the

program. A state agency rehabilitation counselor and/or consultant can help you keep your job by tapping the accommodation resources that will work best for you. If it is determined that you cannot be accommodated and there is not another reassignment job possibility within your company, then you would become eligible for the full gamut of vocational services that your state provides.

The state vocational rehabilitation agency can pay for or conduct a vocational assessment with you in order to identify your transferable skills and your new job goals. Agency personnel can also provide you with neuropsychological testing, which includes not only intellectual assessment but specific testing relating to memory, speed of information processing, and other cognitive concerns that may affect you as someone with MS. As reviewed in chapter 10, neuropsychological assessment is extremely helpful in enabling people to identify cognitive strengths and areas of weakness that need to be accommodated or worked around. As your job placement effort comes into focus, a state agency counselor may pay for other services for you, such as personal adjustment counseling, clothing for job interviews, support with transportation or gas funding, and so forth.

Often, the most helpful aid a state vocational rehabilitation counselor can provide is direct job placement assistance if you need it. This could include hiring a community placement specialist to work with you as someone seeking a full- or part-time job. In some instances, a rehabilitation consultant can be hired to establish a home-based position or assist you with a self-employment plan. You may or may not need direct representation in getting a job, but many others do need some representation from a rehabilitation agency. This may be due to the specific job being sought or to specific accommodation needs. In other instances, because of cognitive concerns, some job coaching or paid coworker mentoring may be needed, so that you can learn critical job skills to keep a job. State vocational rehabilitation (VR) may also pay part of your salary during a period of on-the-job training (OJT) with an employer. If you have no transferable skills, this last item may be your fastest route to new employment and financial stability.

Community Job Tryout: Department of Labor (DOL) Waiver

If it is unknown whether you can continue to work at your job or work effectively in relation to a new job goal, a community-based assessment or work trial period can be extremely beneficial. Under the 1993 Department of Labor (DOL) waiver (see appendix B), an individual with disability has a total of 215 hours to try out a nonpaid job for purposes of vocational exploration, establishing task proficiency, and training or skill-building.

The state vocational rehabilitation counselor often will pay a community rehabilitation provider to establish a community-based assessment (CBA) using this DOL waiver. If you are someone with MS, and you are experiencing fatigue, pain, new learning challenges, or other problems, and you need to try out some type of cognitive or physical accommodation, using these 215 hours can be quite helpful. You may need to present the DOL waiver to your state rehabilitation counselor (see appendix B) because many counselors are unfamiliar with it. Unfortunately, most people in personnel or human resources departments are also unfamiliar with this “tryout approach.” The 215 hours, of course, do not need to be used completely; some individuals try out for only a few days or weeks to get the information they need.

If you are on medication and recovering either from initial symptoms or an exacerbation of MS, you may want to try out a job on the unpaid basis (e.g., beginning a few

TIP: Copy appendix B and have it with you to consult, if necessary, while you are interviewing. It can be your ticket to getting back to work!

hours a day with gradual increases) in order to establish the accommodations that will work for you, including the length of your workday. In other cases, it may be more important to establish what you would enjoy doing in a certain type of job, and gain some experience in that activity. Some people can determine their comfort level and work capacity only by utilizing this tryout mechanism (e.g., twenty-five hours a week or a staggered three-day workweek).

Labor and Industry Insurance Costs

The Labor and Industry (L&I) insurance costs are typically paid by the state vocational rehabilitation agency or by the specific rehabilitation provider that has set up the tryout for you and is monitoring your progress. **Note:** Although the 215 hours granted to you adds up to less than six weeks when employed full-time, working only a few hours a day and graduating upwards can involve several months. This may be critical information for you as you mount a full-blown effort at working, versus the effort to move toward disability insurance or Social Security Disability Income (SSDI). Finally, you might decide to pursue SSDI, but work part-time and earn less than Substantial Gainful Activity (SGA), which is currently set by the Social Security Administration at about \$830 monthly (periodically adjusted upward).

FINDING A JOB ON YOUR OWN

You might be ineligible for state vocational rehabilitation services due to your personal financial status and your savings or the earnings of your spouse or significant other. You may then have to seek a new full- or part-time job on your own. If you are certain of a job goal based on your education and prior work experience, you can target your efforts and use your state's WorkSource offices (see the upcoming section WorkSource: The State Employment Agency), Web site searches, and so forth.

If your goal is not clear to you, often vocational counseling can be obtained from an area community or state college on a nonpaid or paid basis. Also, you can choose to hire a private rehabilitation counselor or counseling psychologist. The National Multiple Sclerosis Society Web site can be very helpful for dealing with employment decisions and issues. The national Epilepsy Foundation Web site's, "Career Support Center" workstation linked to "Programs" on the home page is ideally linked to job search Web sites for those with and without a disability. It is a splendid resource.

Targeting Your Job Goal

Rumrill (1996, 81) and others have suggested that to be successful in your job search, you must identify the following: (a) specific job options, (b) geographical area(s) of focus, (c) the work values that are important to you, and (d) a series of potential contacts who can aid you in securing positions in this area(s).

In some instances, it will be difficult to identify job options immediately and you will need to consider using vocational interest inventories, such as the Strong Interest Inventory, the Career Assessment Inventory, or a state occupational information system inventory (as available on the Internet), in order to develop new goals. Counselors at community colleges, universities, and state employment offices can help you to "tweak" and refine your goals for your particular residential area. These counselors are often "low-cost" or "free" when compared to the fees charged by private counselors or psychologists.

Career development classes, taken through college or community college extension departments, can be helpful, although they may be less than optimal. As soon as your goals have been identified, certain types of short-term training can be invaluable to secure positions such as medical coder, medical billing specialist, security system installer, pest-control technician, and so forth. Other types of training are more long-term and the question for each individual is “How much time can be devoted to retraining, given your age and financial needs?”

Getting Through an Employer’s Door

The focus of your job search is securing interviews, not simply mailing or e-mailing your résumés.” Note that informational interviews are easier to schedule than actual job interviews, but they are very important in this job-seeking process and are invaluable for developing a contact base and for networking. Informational interviews still can require very targeted and consistent efforts from you.

Checklist 10: Getting Informational Interviews

The steps below, in checklist format, describe a systematic procedure for you to get some informational interviews (e.g., twenty-eight well-targeted mailings can result in five to eight informational interviews). Once the informational interview has been secured, your job will be to maximize the value of these interviews.

1. Have I identified my job goal? _____
2. Is my résumé established and refined (with critiques) from professional/significant others?

3. Have I a cover letter that asks for an informational interview in relation to a specific type of job? _____
4. Have I developed my “mass” mailing list to include specific contacts (names) from targeted areas of Chamber of Commerce directories, telephone yellow pages, business associations, unions, and other relevant groups? _____
5. Did I conduct my mass mailing and develop a tracking book? _____
6. All my targeted individuals are to be called within ten days from mailing the informational interview requests. If informational interview request is denied or the interview is unsuccessful relative to job procurement, did I ask interviewer for the names of other potential contacts? _____

(Note: In each informational interview, employers can be informed about the incentives for hiring a qualified worker with a disability, e.g., tax credits, on-the-job training funding from state vocational rehabilitation office, federal tax deductions and credits for worksite accommodations, and any other incentives for employers to hire disabled workers. See appendix C.)

7. All informational interviewers and contacts identified through them are followed up every two weeks. _____

If no progress is made after a period of months, establish a new job goal and return to step 1 above to redo the entire process. Note that it is important to maintain tracking forms to follow up on your mass mailing. You can use the following example in worksheet 16 as a model for your tracking form.

WORKSHEET 16: MASS MAILING TRACKING FORM						
Contacts	Company Address	Phone	Called for Interview Y/N	Interview Date	Follow-ups	Other Information
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						

There are many resources to help you develop your cover letter and refine your résumé. See Ryan’s *Job Search Handbook for People with Disabilities* (2000). The informational interview will give you an opportunity to establish rapport with someone in your desired field, update your job-market information, get advice on your job search, obtain referrals, and so forth. When calling for the interview, make sure the employer knows that you are simply seeking information and do not want to take more than twenty minutes of his or her time. Be prepared for the following:

- Discuss your background and goals for three to four minutes.
- Describe five or more of your special skills and personal qualities as a part of this three-to-four minute presentation.
- Be prepared to ask the employer questions about the company’s job(s) of interest to you and about the company itself. Draw out the employer by your interest in (and knowledge of) the company.

- If your background is inadequate or barriers are presented, seek feedback for overcoming them. Also, ask feedback about your résumé.

GENERAL EMPLOYMENT RESOURCES

A number of state, federal, and local resources are described in this chapter. Many of them can be linked to your locale through the Epilepsy Foundation Web site Career Support Center link as mentioned previously.

WorkSource: The State Employment Agency

WorkSource state employment agencies are located throughout each state. These centers offer employers all the information, technology, and personal services that are available for finding and hiring employees. You can post your résumé in the state WorkSource databank for potential matching to an employer's needs within your community. Career counseling is available, but the quality can vary both within and across states.

You, however, have access to the Internet and to public and private job search engines. If you were laid off or terminated from a position, you can receive your unemployment insurance payments (if eligible) through these centers as long as you maintain active job seeking. You may have access to short-term retraining funds and almost all WorkSource sites conduct classes on job search and job maintenance.

Several partnering agencies, such as state vocational rehabilitation, emergency retraining programs, and so on, often can be found at these sites. The concept behind WorkSource is to house or link all available employment resources within the one site. Contact with a disability specialist, veteran's specialist, or other advocate (as appropriate) at the site can turn out to be invaluable to you.

National Multiple Sclerosis Society Affiliates and Other MS Associations

Although most MS affiliates or associations don't have employment programs, a few do have them. Or you may be referred to a knowledgeable state vocational rehabilitation agency provider or other well-informed vocational rehabilitation service providers. Staff at these associations are also informed about SSDI issues, application procedures and strategies, discrimination issues, and so on, and they can be helpful on a number of employment-related matters.

Kent State University Employment Assistance Service, Akron, Ohio

The above-named service, under the direction of Dr. Phil Rumrill, actually can provide you with MS-specific job accommodation recommendations at no cost if your local MS association has a subscription with them. Unfortunately, to date, only the following affiliates have subscribed to this service for their clients: Greater Illinois (Chicago); Georgia; Channel Islands (Santa Barbara, California); Greater Connecticut (Hartford to New York suburbs); Northeast Ohio (including Columbus); Ohio Valley (Cincinnati); and Mid-South (most of Tennessee and part of North Carolina). Hopefully, this service soon will expand to your area.

The Ticket to Work Program

The Social Security Administration developed the national Ticket to Work program in which an individual on a Social Security subsidy can be assigned a voucher that can be utilized by any certified employment network (EN) within a state in order to provide that person with job-placement assistance. These employment networks can be diverse: vocational and social services agencies, or businesses within your community, and all state vocational rehabilitation agencies will be ENs. These networks get paid only when you (as a person with Social Security support) secure a job that is substantial gainful activity (SGA) and you terminate your Social Security Disability Income (SSDI) or your Supplemental Security Income (SSI). If the position does not work out, you may get back onto SSDI or SSI automatically, with any accompanying medical coverage. Your “employability” will then be reevaluated while the Social Security subsidy and Medicaid coverage are provided.

The Ticket to Work program was also developed with the assumption that an individual might be using a state’s buy-in mechanism relative to Medicaid if the employer does not provide health insurance. Given national economic constraints, this option may not always be available and you may need to evaluate your medical needs very carefully before dropping the support provided through Medicaid. Individuals seeking only part-time work (below \$830 per month for SSDI) and wishing to maintain their SSDI or SSI support will not qualify for the Ticket to Work voucher. As of 2004, the Ticket to Work system was implemented in every state, but the program was poorly thought-out and it now has lost the confidence of Social Security administrators and may be reformatted as this book goes to press.

Church and Religious Groups

Many church and religious groups have made efforts to provide employment assistance for their parishioners and friends due to today’s high unemployment levels. This can involve the establishment of a job bank, which is available to community members outside of the religious group. In many cases, this can involve support of a job search or a networking group at the facility. Your church or synagogue, therefore, should not be overlooked as a potential source of employment referrals. Many people list their desired job in the church or synagogue weekly newsletter, which is often distributed at religious services. Faith-based communities frequently want to take care of their own and may reach out to you.

Professional Trade Organizations

Some associations (e.g., medical associations) have their own employment office reflecting the diverse employment needs of their members. In other instances, union and other trade associations have representatives who may know about apprentice and other training access routes for those seeking work in a specific field.

Temporary Jobs

Although you may have a specific job goal in mind, it can be beneficial to work one to two days per week (or more) at a temporary job. This would be not only for your cash flow, but also to increase your job-related contacts within your community. Temporary work is also helpful in alleviating depression and

anxiety. Today, many temporary employment agencies provide a range of both skilled and unskilled employees to employers. Some companies will hire permanently only from the temporary pool of workers currently working for them. (This is known as “temp to perm” hiring.) Basically, these companies use the temporary help option as a screening mechanism for hiring quality permanent employees. Temporary agencies are a burgeoning access point to viable jobs in our economy.

College/Training Facility Employment Offices and Former Teachers

Most colleges or training facilities allow their graduates to return to their job-placement offices despite the fact that they may be years away from graduation. This is a resource that is not to be overlooked. In some cases, individuals return to former teachers (some of whom assisted them in securing a first job) for leads and additional contacts. Contacts made through your prior training facility and your teachers may be very important and should be contacted regularly. Some teachers will refer you to successful alumni who will then make that extra effort for you as a fellow or sister alumnus.

Chambers of Commerce

Most Chambers of Commerce have a monthly (low- or no-cost) social gathering at which it can be reasonably easy to meet employers from your community. Don't miss them. Bring your résumé, your best social small talk, and your clearly prepared job goal conversation. Typically, Chamber of Commerce directories are categorized by different types of businesses, provide contact personnel, and are free or inexpensive from the organization. This can be a great resource for getting those informational interviews close to home. A local Chamber of Commerce may also provide access to a job close to home.

Fraternal and Charitable Organizations

Fraternal and charitable organizations such as Rotary, Elks, Shriners, or Kiwanis draw their membership from diverse community businesses. Try attending a meeting as a guest of a member and when you are introduced, be prepared to discuss your job goal succinctly. Every Rotary club in the world has a Vocational Services committee. Try to contact this committee's chairperson to make your job needs known. Such organizational officers are generally receptive and may make the extra effort to make member contacts for you.

Conclusion

Hopefully, this chapter has provided you with a starting point for planning your job maintenance strategy or your job search efforts. Efforts were made to provide you with a range of available community resources. The descriptions provided are not exhaustive. Other resources can be identified through your local chapter of the National Multiple Sclerosis Society. You are limited only by your own creativity in these areas. Take breaks when your job search becomes exhausting, but stay the course because ultimately it can be very rewarding (in multiple ways) to be a member of the workforce.