



National  
Multiple Sclerosis  
Society

## Employment Resources For Self Advocacy

This guide is intended to help people with multiple sclerosis learn more about their employment options and to be proactive in using the legal protections and resources available to maintain employment and/or re-enter the workforce. Employment may be full-time or part-time, working from home, or self-employment.

Knowing how to handle disclosure on the job, how best to approach your employer about your condition, and what you have the right to ask for are paramount. This is not a decision to make lightly. Do your research, explore all of your options, and have a clear plan in mind. Doing all these things will maximize the chances of a successful outcome. Knowing where to turn in case things don't go as planned is also important.

A useful guide throughout your course of action is the National MS Society's Self-Advocacy Worksheet (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/download.aspx?id=8130>). You may refer to it to assess your circumstances, concerns or needs, and to identify your aims for self-advocating in the employment arena. A sample case study applied to this worksheet is available at <http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-and-employment/download.aspx?id=8132>.

### Impact of MS on Employment

Research shows that the majority of people with MS leave the workforce prematurely and voluntarily. It is important not to make a rash decision about your employment.

One of the first things you may want to consider is the effect your MS may be having on the job. In order to do so, complete the exercise "Analyzing the Effects of MS on Work" at <http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-and-employment/download.aspx?id=8135>.

The National MS Society offers *Career Crossroads: Employment and MS*. This program, to be completed in small group settings or as a self-study program, covers many of the common employment concerns facing individuals with MS as well as other chronic illnesses. Topics include the impact of MS on employment, legal protections, disclosure, accommodations, resources, and planning ahead. Training components are available on a DVD, with an accompanying participant guide, available from the National MS Society at 1-800-344-4867. Each segment

is approximately 15 minutes in duration and designed to be accompanied with the participant guide.

It is important to recognize that the relationship between work and MS is two-way. The symptoms of your MS may impact your job, but your work can also impact how you feel away from your job. Some useful materials to review include the following:

- **Staying in the Game: MS and Employment** <http://www.nationalmssociety.org/living-with-multiple-sclerosis/employment/index.aspx>. For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867
- **National MS Society brochure *Should I Work?*** <http://www.nationalmssociety.org/multimedia-library/brochures/employment-issues/download.aspx?id=69> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.
- **A Place in the Workforce** <http://www.nationalmssociety.org/multimedia-library/brochures/employment-issues/download.aspx?id=68> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.
- **Focus on Employment** <http://www.nationalmssociety.org/multimedia-library/brochures/employment-issues/download.aspx?id=644> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.

### **Know Your Rights**

Several laws may offer you certain protections and options on the job. These deal with more than just discrimination and requesting accommodations. They also include health insurance protections. Therefore, it is important that you are aware of your legal rights in the workplace.

**Americans with Disabilities Act (ADA)** — protects against discrimination in the workplace and allows you to request reasonable accommodations. Consider these questions:

- Does my employer have 15 or more employees?
- Do I meet the definition of a person with a disability under the ADA and the ADA Amendments Act of 2008?
- Can I perform the essential functions of my job with or without accommodations?
- If you answered yes to these questions, the ADA may offer certain protections in the workplace.

Resources regarding the ADA and other legal protections include the following:

- **National MS Society brochure *ADA & People with MS*** <http://www.nationalmssociety.org/multimedia->

- [library/brochures/employment-issues/download.aspx?id=66](http://www.nationalmssociety.org/library/brochures/employment-issues/download.aspx?id=66) For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.
- **National MS Society brochure *Know Your Rights: A Legal Guide for People Living with MS***, <http://www.nationalmssociety.org/multimedia-library/brochures/employment-issues/download.aspx?id=5822>. For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.
  - **Job Accommodation Network (JAN)** <http://askjan.org/> and <http://askjan.org/links/adalinks.htm>. For a copy of this information or to speak with JAN, call 1-800-526-7234.
  - **Disability and Business Technical Assistance Center (DBTAC)**, <http://www.adata.org> For more information about the ADA from your local DBTAC, call 1-800-949-4232.

**Rehabilitation Act of 1973**, amended more recently, may also provide some protection.

- Do I work for a federal government agency? If so, I may be covered under the Rehabilitation Act as opposed to the ADA.

**State and Local Laws** — Review these. Sometimes they offer anti-discrimination protections similar to or greater than the ADA. For a list of civil rights agencies familiar with local protections, check out <http://askjan.org/cgi-win/TypeQuery.exe?037>.

**Family and Medical Leave Act (FMLA)**. Provisions within it may allow you job-protected time off from work.

- <http://www.dol.gov/whd/fmla/index.htm>
- <http://www.dol.gov/dol/compliance/comp-fmla.htm> U.S. Department of Labor, 1-866-487-2365

**Health Insurance Portability and Accountability Act (HIPAA)** This Act addresses maintaining health insurance coverage and pre-existing conditions.

- <http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/health-insurance/hipaa/index.aspx> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.
- <http://www.dol.gov/ebsa/newsroom/fshipaa.html>, U.S. Department of Labor, 1-866-444-3272.

**Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA)**. This Act permits you to continue to buy into health insurance coverage when leaving your job. Learn more about it.

- <http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/health-insurance/cobra/index.aspx> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.
- [http://www.dol.gov/ebsa/faqs/faq\\_consumer\\_cobra.html](http://www.dol.gov/ebsa/faqs/faq_consumer_cobra.html) U.S. Department of Labor, 1-866-444-3272

### What about Disclosure?

Often, one of the first questions you may ask yourself is, “Do I need to disclose my MS to my employer?” There is no clear answer to this question. There are many factors that come into play that might lead someone to disclose or not to disclose. Often, disclosure in the workplace relates directly to requesting accommodations.

If you are thinking about disclosing your MS diagnosis, you may want to complete the National MS Society’s Employment Disclosure Exercise (<http://staging.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-and-employment/download.aspx?id=8134>) and the Disclosure Decision Worksheet (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-and-employment/download.aspx?id=2034>).

Key questions you may be thinking about include:

- Should I tell my employer?
- Do I tell my human resources department, my supervisor, my co-workers, or all of the above?
- Should I disclose when I am initially diagnosed or when my symptoms are obvious? What exactly should I tell my employer?
- Do I tell my employer I may miss work periodically due to disease exacerbations?
- How do I manage the information after I’ve told my employer?

These are all very personal decisions, with no clear-cut answers. Ask yourself, “What makes me think I should or want to disclose my diagnosis?” Evaluate your circumstances.

- **Disclosing MS in the Workplace Web site tool** <http://www.nationalmssociety.org/living-with-multiple-sclerosis/employment/disclosure/index.aspx> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.
- **Career Crossroads: Employment and MS DVD segments** For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.

- **National MS Society Basic Facts Sheet *Disclosure***  
<http://www.nationalmssociety.org/multimedia-library/brochures/newly-diagnosed/download.aspx?id=47> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.
- **Information for Employers** <http://www.nationalmssociety.org/multimedia-library/brochures/employment-issues/download.aspx?id=67> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.

If, after you evaluate the pros and cons, you decide to disclose your MS diagnosis to your employer, write your disclosure script and practice it. Plan ahead. Keep it simple. Be positive.

### **How Can I Succeed on the Job with Accommodations?**

What are reasonable accommodations and how can they help me succeed on the job? Am I having difficulty performing the essential functions of my job?

Do a self-assessment and determine if your symptoms are affecting your ability to effectively and efficiently perform your job duties. Ask trusted colleagues or friends if they notice an impact of your symptoms on the job. The National MS Society's reasonable accommodations exercise may be helpful.

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-and-employment/download.aspx?id=8137>

Consider resources regarding workplace accommodations.

- **Job Accommodation Network (JAN)**,  
<http://askjan.org/>, 1-800-526-7234
- **JAN publication specifically addressing accommodating MS in the workplace**, <http://askjan.org/media/MS.html> or  
<http://askjan.org/media/downloads/MSA&CSeries.pdf>  
1-800-526-7234
- ***The Win-Win Approach to Reasonable Accommodations: Enhancing Productivity on Your Job*** <http://www.nationalmssociety.org/multimedia-library/brochures/employment-issues/download.aspx?id=70> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867

### **How do I negotiate reasonable accommodations?**

The reality is that you are responsible for knowing what to request and for proactively requesting reasonable accommodations in the workplace. Resources are available.

- **The Employees' Practical Guide to Requesting and Negotiating Reasonable Accommodations under the Americans with Disabilities**

**Act (ADA)** To request a copy from the Job Accommodation Network (JAN), phone 1-800-526-7234.

- ***The Win-Win Approach to Reasonable Accommodations: Enhancing Productivity on Your Job***, <http://www.nationalmssociety.org/multimedia-library/brochures/employment-issues/download.aspx?id=70> For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867.
- **Should my request for reasonable accommodations be in writing?**  
This oftentimes is on a case-by-case basis. Some employers may request written documentation. For others, a verbal request is sufficient. Review a sample written request for a job accommodation at <http://askjan.org/media/accommrequestltr.html> or call JAN at 1-800-526-7234 to request a copy.

### **Dealing with Employment Discrimination**

If you believe you are being discriminated against on the job, resources are available.

- The United States Equal Employment Opportunity Commission (US EEOC) enforces Title 1 of the Americans with Disabilities Act (ADA). Visit <http://www.eeoc.gov/> or phone: 1-800-669-4000.
- For a state-by-state listing of local protection and advocacy organizations, visit <http://www.napas.org/index.htm> or phone 1-202-408-9514.
- To identify your local Office of Civil Rights/Office of Human Relations, check out your state or county government listings. A list of state civil rights agencies can be found online at <http://www.jan.wvu.edu/cgi-win/TypeQuery.exe?037>.
- Consider the local American Bar Association Lawyer Referral Line, <http://www.abanet.org/legalservices/lris/directory/> or contact the National MS Society at 1-800-344-4867 to obtain additional legal resources including legal referrals, community legal agencies, etc.

And, remember to keep a log of activity that is occurring. This may be useful to you, if you choose to pursue legal action.

### **Don't Do It Alone — Resources You Can Turn To**

- The **National MS Society** has a considerable number of resources to assist you. These include a variety of employment-related publications and brochures, the program **Career Crossroads: Employment and MS**, an employer DVD entitled **MS in the Workplace: A Guide for**

**Employers**, and referrals to additional employment resources. Call your chapter at 1-800-344-4867 or visit the National MS Society Web site and begin your research here: <http://www.nationalmssociety.org/living-with-multiple-sclerosis/employment/index.aspx>.

- **Vocational Rehabilitation (VR)**. Each state has an agency that exists to assist individuals with disabilities in gaining, maintaining, and retaining employment. State-specific contact information is at <http://askjan.org/cgi-win/TypeQuery.exe?902>
- The **Job Accommodation Network (JAN)** offers information about working with a disability, job accommodations and ADA expertise on employment issues. It is a free service funded by the U.S. Department of Labor, Office of Disability Employment Policy (<http://www.dol.gov/odep>). You can reach JAN at 1-800-526-7234 or <http://askjan.org/> JAN also has extensive information about self-employment and entrepreneurship. This information can be found at <http://askjan.org/entre/>
- The **New Freedom Initiative's Online Resource for Americans with Disabilities** has disability related resources and information, including extensive information about employment. Information can be found at <http://www.disability.gov>.
- The mission of the **U.S. Department of Labor Office of Disability Employment Policy (ODEP)** is to provide national leadership on disability employment policy. Visit <http://www.dol.gov/odep/> for a variety of publications and initiatives, or contact 1-866-633-7365.
- Visit <http://www.ada.gov> or phone 1-800-514-0301 for information sponsored by the **U.S. Department of Justice** regarding the **Americans with Disabilities Act (ADA)**.
- **Work Incentive Planning and Assistance (WIPA)**. The goal of the Work Incentive Planning and Assistance (WIPA) is to better enable Social Security beneficiaries to make informed choices about returning to the workplace, if currently receiving Social Security Disability benefits. Find out what impact work could have on your benefits. **Visit:** <http://www.socialsecurity.gov/work/wipafactsheet.html> and click on Service Provider Directory to find a state-by state listing of WIPA programs.
- **Regional Disability and Business Technical Assistance Centers (DBTAC and ADA Centers)** are 10 federally funded regional centers that provide information, training and technical assistance on the ADA. Each center works with local business, as well as disability, governmental, rehabilitation and other professional networks, to provide current ADA information and assistance, placing special emphasis on meeting the needs of small businesses. The DBTACs can make referrals to local

sources of expertise for reasonable accommodations. Visit <http://www.adata.org> or phone 1-800-949-4232.

- **Employer Assistance and Recruiting Network (EARN).** EARN is a free service offered by the U.S. Department of Labor Office of Disability Employment Policy ([www.dol.gov/odep](http://www.dol.gov/odep)) that provides employment and disability information. Visit [www.earnworks.com](http://www.earnworks.com) or [http://www.earnworks.com/job\\_seekers/Tools/index.asp](http://www.earnworks.com/job_seekers/Tools/index.asp) for employment sites and resources.
- **One-Stop Employment Centers.** To locate a comprehensive job center offering aid to job seekers in your community, visit America's Service Locator at <http://www.servicelocator.org> or phone 1-877-US2-JOBS (1-877-872-5627).