

Table of Contents

[Impacts Of MS On Employment](#)

[Know Your Rights](#)

[What About Disclosure?](#)

[How Can I Succeed on The Job with Accommodations?](#)

[How Do I Negotiate Reasonable Accommodations?](#)

[Dealing With Employment Discrimination](#)

[Don't Do It Alone – Resources You Can Turn To](#)

[Self-Advocacy Worksheet](#)

[Prepare – Determine Your Method & Timing](#)

[Analyzing How MS Impacts Your Work - Worksheet](#)

[Disclosure Decision Worksheet](#)

[Employment Disclosure Worksheet for Self-Advocacy](#)

[Analyzing Your Need for Reasonable Accommodations Worksheet for Self-Advocacy](#)

Summary

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](#). 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 on page 9 of this guide.

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.

[Analyzing How MS Impacts Your Work - Worksheet](#)

Description: One of the first things you may want to consider is the effect your MS may be having on the job. This worksheet helps analyze those effects. Provided by the National MS Society.

Employment Matters: Managing MS in the Workplace

Description: The National MS Society's resource, Employment Matters: Managing MS in the Workplace, can help individuals learn to navigate the complexities of managing MS and work through this [six part video series](#) and companion [toolkit](#). Topics include the impact of MS on employment, being proactive, legal protections, disclosure, accommodations, resources and assistive technology.

[Working with MS](#)

Description: A National MS Society booklet for employees living with MS. 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.

Know Your Rights

[Know Your Rights](#)

Description: A legal guide for people living with Multiple Sclerosis provided by the National MS Society. There are several laws that may offer you certain protections and options on the job, such as when it comes to discrimination, requesting reasonable accommodations and protections for health insurance.

Americans with Disabilities Act (ADA)

(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 include the following:

[ADA & People with MS](#)

Phone: 1-800-344-4867, for a copy of this information or to speak with an MS Navigator®.

[Job Accommodation Network \(JAN\)](#)

Phone: 1-800-526-7234

[ADA National Network](#)

Phone: 1-800-949-4232

Rehabilitation Act of 1973

Amended more recently, may also provide some protection for those who work for a federal government agency. Follow these links for more information:

Website: <http://www.eeoc.gov/laws/statutes/rehab.cfm> and http://www.eeoc.gov/federal/fed_employees/complaint_overview.cfm

State and Local Laws

Description: Review this list of civil rights agencies familiar with local protections.

Family and Medical Leave Act (FMLA)

Description: Provisions within FMLA may allow you unpaid, job-protected time off from work.

Phone: 1-866-487-2365, U.S. Department of Labor

Health Insurance Portability and Accountability Act (HIPAA)

Description: This Act addresses maintaining health insurance coverage and pre-existing conditions.

Phone: 1-877-696-6775, U.S. Department of Health & Human Services

National MS Society Webpage - HIPAA

Phone: 1-800-344-4867, for a copy of this information or to speak with an MS Navigator®.

Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA)

Description: This Act permits you to continue to buy into health insurance coverage when leaving your job.

Phone: 1-866-444-3272, U.S. Department of Labor

National MS Society Webpage - COBRA

Phone: 1-800-344-4867. For a copy of this information or to speak with an MS Navigator®.

What About Disclosure?

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.

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. These evaluation exercises and resources provided by the National MS Society can help:

Employment Disclosure Worksheet for Self-Advocacy

Disclosure Decision Worksheet

[Disclosing MS in the Workplace Website Tool](#)

[Employment Matters: Managing MS in the Workplace](#)

[Disclosure: The Basic Facts](#)

[Information for Employers](#)

Phone: 1-800-344-4867, for a copy of these resources or to speak with an MS Navigator®.

If you decide to disclose your MS diagnosis to your employer after you've evaluated the pros and cons, 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 perform your job duties effectively and efficiently. Ask trusted colleagues or friends if they notice an impact of your symptoms on the job. Utilize this exercise on analyzing your needs for self-assessment:

[Analyzing Your Need for Reasonable Accommodations Worksheet for Self-Advocacy](#)

Phone: 1-800-344-4867, for a copy of these resources or to speak with an MS Navigator®.

Consider these resources for workplace accommodations:

[Job Accommodation Network \(JAN\)](#)

Phone: 1-800-526-7234

[Accommodation and Compliance: Multiple Sclerosis](#)

Description: Job Accommodation Network (JAN) publication on accommodating MS.

[The Win-Win Approach to Reasonable Accommodations: Enhancing Productivity on Your Job](#)

Phone: 1-800-344-4867, for a copy of this information or to speak with an MS Navigator®.

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 \(ADA\)](#)

Description: Review a summary of some of the most frequent issues that employees have regarding accommodations and ADA compliance. Learn more about JAN's practical ideas for resolving them. They also have a [sample request for a job accommodation](#).

Phone: 1-800-526-7234, to request a copy from the Job Accommodation Network (JAN).

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 \(US EEOC\)](#)

Description: The US EEOC enforces Title 1 of the Americans with Disabilities Act (ADA). See their webpage on [disability discrimination](#).

Phone: 1-800-669-4000

[State Civil Rights Agencies](#)

Description: A locator to identify your local Office of Civil Rights/Office of Human Relations.

For legal advice:

[American Bar Association](#)

[National Employment Lawyers Association](#)

National MS Society

Phone: 1-800-344-4867 to obtain additional resources including legal referrals and community legal agencies.

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 — Employment Resources You Can Turn To

[National MS Society](#)

Description: The National MS Society has a considerable number of resources to assist you. These include a variety of employment-related publications and brochures and referrals to additional employment resources. Call or visit online to begin your research.

Phone: 1-800-344-4867 to speak with an MS Navigator®.

[Vocational Rehabilitation \(VR\)](#)

Description: Each state has an agency that exists to assist individuals with disabilities in gaining, maintaining and retaining employment. Contact your local vocational rehabilitation office.

[Job Accommodation Network \(JAN\)](#)

Description: 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. Its development has been achieved through the collaborative efforts of ODEP, West Virginia University and private industry throughout North America. JAN also has extensive information about [self-employment and entrepreneurship](#).

Phone: 1-800-526-7234

[U.S. Department of Labor Office of Disability Employment Policy \(ODEP\)](#)

Description: The mission of the U.S. Department of Labor Office of Disability Employment Policy (ODEP) is to provide national leadership on disability employment policy. A variety of publications and initiatives are available.

Phone: 1-866-633-7365

[Americans with Disabilities Act \(ADA\)](#)

Phone: 1-800-514-0301, U.S. Department of Justice

Work Incentive Planning and Assistance (WIPA)

Description: The goal of the 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 with this brochure from the Social Security Administration, [Working While Disabled: How We Can Help](#). Find [local assistance here](#).

Phone: 1-866-968-7842

Regional ADA Centers

Description: 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. Special emphasis is placed on meeting the needs of small businesses. The ADA centers can make referrals to local sources of expertise for reasonable accommodations.

Phone: 1-800-949-4232

Employer Assistance and Recruiting Network (EARN)

Description: EARN is a free service offered by the U.S. Department of Labor Office of Disability Employment Policy that connects employers seeking quality employees with skilled job candidates.

Phone: 1-866-327-6669

Career One-Stop Employment Centers

Description: To locate a comprehensive job center offering aid to job seekers in your community.

Phone: 1-877-US2-JOBS (1-877-872-5627)

Self-Advocacy Worksheet

(Sample Responses for Employment)

PREPARE & TAKE ACTION

This worksheet is designed for you to organize your thoughts and actions for effective self-advocacy in various life settings. Based upon your situation, some steps may be irrelevant, and others may need to be revisited. Review the entire worksheet before you begin. **Consider and respond only to what is relevant to your circumstances.** You can access a [blank template of this worksheet here](#).

ORGANIZE

1. Describe your issue or concern and your preferred solution to resolve it. **Practice saying it.**

CAUSE Describe the cause of your unique situation.	I am experiencing severe fatigue that is impacting my ability to do my job.
EFFECT Summarize what you aim to change. Describe your key intent.	I would like to learn ways to accommodate my MS symptoms at work and determine the best way to request them so I can continue working.
ISSUE <i>Create a summary statement.</i>	It is important for me to continue working. To do so, I need to ask for accommodations on the job. I will need to do research to determine how best to approach my employer and to request a reasonable accommodation.
BECAUSE	of certain MS symptoms, I am having difficulty working.
I NEED OR I WANT	accommodations to continue working successfully.

2. List the pros and cons of taking steps toward self-advocacy. **Identify positive and negative aspects of your current situation, along with the potential risks and rewards associated with self-advocacy.** Identify what you believe must be addressed to meet your unique needs or special concerns. Circle the aspects most important to you.

Pros	Cons
Working brings in a paycheck and provides benefits to me and my family.	Working makes my fatigue even worse.
Working gives me a sense of purpose.	I will need to disclose my condition.
Accommodations will help me to be more productive and ultimately help the bottom line of my company.	I am scared I will be fired by asking for what I need.
Hopefully, with accommodations, it will allow me greater job security, as I know I will be able to keep up with the work I have to perform.	I may bring attention to myself by asking for accommodations and be seen as getting preferential treatment.

3. **Research.** Identify questions relevant to your situation or circumstances. Cite references, resources, or trusted advisers for answers to these.

Question	Reference, Resource, or Contact Information	Outcome
Do I have the right to ask for accommodations?	<ul style="list-style-type: none"> National MS Society ADA & Win-Win Approach brochures and employment publications Job Accommodation Network (JAN) ADA Center 	My employer does abide by the ADA and that law offers me the option of requesting reasonable accommodations.
What accommodations could help to manage fatigue?	<ul style="list-style-type: none"> Job Accommodation Network (JAN) National MS Society 	Flexible work arrangements and/or hours could prove useful.
What is the best way to ask for accommodations?	<ul style="list-style-type: none"> Job Accommodation Network (JAN) National MS Society 	Can ask in person and/or in writing. If in writing, use sample accommodation request letter from JAN.
What do I do if request denied?	<ul style="list-style-type: none"> Job Accommodation Network (JAN) U.S. Equal Employment Opportunity Commission (EEOC) National MS Society Local office of civil/human rights 	Denial may be in violation of ADA — can contact EEOC to file claim or call National MS Society to get referral to attorney and local resources.

4. Summarize key research findings and communications. What did you learn about your rights? What about your responsibilities?

My Rights	My Responsibilities
ADA allows me right to ask for reasonable accommodations.	Responsibility for coming up with accommodations is mine.
To control how much information is disclosed to my employer and that info is to be kept confidential.	Determine the best time to ask for accommodations and how best to present them — in person, in writing, both.
To stay active in the workplace and be a productive member of society.	Determine correct person to request accommodations from.
To file claim if accommodations completely denied for no apparent reason.	Have back-up ideas in mind if initial accommodations not feasible.

5. **Identify who has authority regarding your situation.** Begin by determining the front line for customer service, but also be alert for names and contact information of those at higher levels. Put a star next to the name of your first point of contact.

I will make this request of my immediate supervisor and be open to involvement with the human resources department. I can also refer them to JAN to discuss accommodation alternatives. Ultimately, if need be, I can contact the EEOC and an employment attorney.

6. Brainstorm possible solutions to address your concern.

I will need to request a reasonable accommodation to manage my extreme fatigue on the job. I anticipate asking for some flexibility in the work environment and schedule, especially telecommuting.

7. Review your rights and responsibilities. Revisit question 4 and 6. Put a star next to your preferred solution(s), given your rights and responsibilities.

8. Anticipate objections or resistance to your preferred solution(s). Summarize your responses to the likely arguments made in response to your request. Refer to information you can use to support your argument.

Objection	Response	Reference or Resource <i>in support of your response</i>
Will not allow for telecommuting	Propose altering work schedule or allowing for naps	National MS Society publications JAN EEOC publications
Will not make any accommodations at all	Will file claim of discrimination	EEOC county government Office of Human Rights

9. Establish a fallback position or bottom line if your preferred solution is not adopted. What are you are willing to settle for?

Example: If I am not allowed to work from home a few days per week, I hope to be able to adjust my schedule and/or combine breaks so I can take a brief nap if necessary to manage my fatigue. I would be willing to work from home only one day per week or do it on a trial basis and evaluate how it is working for me and for my employer.

What options do you have if your bottom line is not met? Is there a formal review or appeal process? Conduct initial research and determine next steps for an appeal process.

Example: If my employer is not willing to accommodate me, I can contact the US EEOC to file formal charges of discrimination. I can also contact my local Human Rights Commission. I can do more research into my options under the ADA by calling JAN and my regional ADA center.

10. Revisit the positive aspects of your situation (see #2 above). Recall these during your self-advocacy journey.

Example: I have worked for my company for over five years and have had positive evaluations. I have a good relationship with my direct supervisor and honestly feel that I am an asset to my company. They are lucky to have me as I have expertise that is valuable to my employer.

Prepare – Determine your Method & Timing

PREPARE

Determine your method and timing. In general, more personal, and less formal communication will be perceived as less threatening. Consider the benefits and drawbacks of initially discussing your situation in person, via phone, or in writing. Identify your preferred option.

If you intend to call or visit in person, remember to consider the most convenient time for your point of contact.

PRACTICE

Draft a letter about your issue and the outcome you hope to see. Revisit it a day or two later. Make any necessary revisions. Be concise, clear, and cordial. Rephrase any aggressive or disrespectful statements. Include complimentary or positive remarks. Show your revised letter to someone whose judgment you respect. Ask for their feedback.

Role play. Practice how you will state your points. Ask a friend to role play with you. Take a turn advocating your point of view. Switch roles. Listen to your partner advocate your point of view. Pretend you are on the phone, too. Discuss what you observed during the exercise.

Rehearse on your own. Deliver your main points in front of a mirror. Listen to your voice: maintain an easy pace and moderate volume. Watch your facial expressions; try to remain relaxed and open.

TAKE ACTION

- Review your work above.
- **Schedule an appointment** by placing a call or writing a letter to the front line of customer service who can address your circumstances.
- **Take detailed notes during your discussion**, including names, dates, and contact information. Save them along with notes from future conversations, and file them in chronological order. Include any correspondence related to your issue, with the results of any research or other documentation.
- **Establish next steps and mutual accountability.** Agree upon a timeframe for next steps or issue resolution.
- **Follow up.** Provide any promised information or resources within the agreed upon timeframe. Renegotiate if you will be delayed, or if your point of contact fails to respond. Offer to provide additional information or resources to resolve any questions. Restate your issue and the outcome you hope to see. Commit to a timeframe for issue resolution.
- **Write a thank you note** if you achieve your desired outcome. This is not only polite but documents your agreement.
 - *Remember, you may need to follow up to ensure your desired outcome.*

- **If you receive no response or an unsatisfactory response**, consider how much additional effort you are prepared to invest. Often, an appeal to a higher level is possible. Research the options relevant to your particular situation. Consider what is at stake to determine whether to proceed.
- If the situation involves family, broadening the discussion to include a trusted counselor or clergy member may be useful.

Analyzing How MS Impacts Your Work - Worksheet

Take a few minutes now to think about the impact of MS on your work. Use the chart provided on the next page to write down your thoughts.

Step 1. In the first column, list your symptoms of MS

Step 2. Rate the impact of each symptom on your work using this scale:

Rating	Description
0	No impact on work
1	Minimal impact on work, occurs rarely
2	Minimal impact on work, occurs occasionally
3	Minimal impact on work, occurs regularly
4	Some impact on work, occurs rarely
5	Some impact on work, occurs occasionally
6	Some impact on work, occurs regularly
7	Significant impact on work, occurs rarely
8	Significant impact on work, occurs occasionally
9	Significant impact on work, occurs regularly
10	I am not able to complete my responsibilities because of this symptom

Step 3. In the third column, list examples of situations at work where this symptom has affected your work performance.

MS Symptoms	Rate Impact	Examples of Impact
Example: <i>Fatigue in afternoon</i>	6	<i>Almost fall asleep at desk, have trouble focusing in afternoon meeting, error rate higher in afternoon</i>

MS Symptoms	Rate Impact	Examples of Impact
Example: <i>Fatigue in afternoon</i>	6	<i>Almost fall asleep at desk, have trouble focusing in afternoon meeting, error rate higher in afternoon</i>

Disclosure Decision Worksheet

Consider the pros and cons of disclosure in your personal situation:

Why Are You Disclosing?	
Anticipated Positive Consequences	Possible Negative Consequences

Whom Are You Disclosing To?	
Anticipated Positive Consequences	Possible Negative Consequences

How Much Are You Disclosing?	
Anticipated Positive Consequences	Possible Negative Consequences

Bottom Line - based on the above, the best alternative for me is:

Employment Disclosure Worksheet For Self-Advocacy

Firstly, remember that disclosure is a highly individual decision.

You may find the following questions helpful in your decision whether to disclose.

	Yes	No
1) Am I avoiding medical treatment to keep my health status secret on the job?		
2) Am I telling lies or making excuses to cover MS symptoms more than once or twice a month?		
3) Have I received negative comments about my effectiveness on the job? A performance evaluation that was less than I expected?		
4) Do I have episodes of staggering, slurring, or falling asleep at my desk?		

If you answered yes to any of the above questions, it may be time to consider disclosing to your employer.

Reflect on your feelings while you consider disclosing to your current employer/new supervisor/new co-worker. Reach out for support if needed - discussing your answers with a person close to you may assist you with this decision.

What are the advantages of disclosing?

What do I hope to gain from disclosing?

What is my biggest fear in disclosing?

What are the disadvantages of disclosing?

If you decide to disclose, you need a game plan with a **three-step approach – research, script writing and practice**. Consultation with an occupational or physical therapist, psychologist, career counselor or your state’s vocational rehabilitation office is highly recommended. Talking to these experts will assist you in your research about the kinds of accommodations that would work for you. Remember to take advantage of the educational support provided by the National MS Society as you go through this process.

Your disclosure script should be specific, brief, and non-apologetic. Keep in mind the perspective of your employer as you write this script. Your employer will be considering the questions:

- Can you do the job?
- Are you reliable and dependable?
- Can you grow in your job and be of value to the company?

Include answers to these questions in your disclosure. Other tips include:

- **Keep it short with few, if any, details about MS.** Focus on symptoms that are interfering with your work. We recommend starting at the lowest level of disclosure and only providing more details if your employer requires it.
- **Keep it non-medical,** avoiding clinical or medical terminology.
- **Relate your request for accommodations to your ability and success** in your job performance (the next section will address specific accommodations).
- Explain that you can do the job and, with (or without) accommodations, **your disability will not interfere with your ability to do the work.**
- Remind your employer that **your need for and use of accommodations may vary** due to the relapsing/remitting nature of your medical condition.
- **Be positive,** focus on your best attributes, and end on a positive note, highlighting the continued good work you will be able to do with the help of accommodations (if any).

The final step of your game plan is practice, practice, practice. Ask your family and friends to critique your script and delivery.

Use the following formula to practice writing your own disclosure script:

I have MS (or a disorder), which affects people differently. In my case, I have (job-related) difficulty with _____ and _____. However, this would not interfere with my ability to perform the duties of the job, if minor accommodations could be made such as _____. With these accommodations, I will _____ (positive statement).

Analyzing Your Need for Reasonable Accommodations Worksheet for Self-Advocacy

Take a few minutes now to analyze your need for reasonable accommodations. Use the chart provided on the next page to write down your thoughts.

Step 1: Using a copy of your job description, list your job functions. (If you are currently between jobs, list the functions of a past job or of a job you would like to have).

Step 2: Decide whether the job function is essential or non-essential and write your decision in the second column.

Step 3: In the third column, jot down those symptoms of your MS which are affecting, or which you fear will affect in the future, your job performance.

Step 4: For your essential job functions, brainstorm possible accommodations to help you manage your symptoms and continue to do your job. Jot these down in column four.

For the non-essential job functions that you are having difficulty accomplishing, think about other tasks that you could do instead of this one (e.g., if you and co-workers share the responsibilities of covering the receptionist during lunch and taking the mail to the mailbox, but you are not able to take the mail to the mailbox any longer, offer to take additional lunch shifts). List these in column four.

Job Function	Essential/ Non-essential	Specific MS Symptoms Affecting Each Job Function	Possible Accommodations /Other Tasks
<i>Example: Taking turns twice a week making coffee</i>	<i>Non-essential</i>	<i>Can't walk all the way to the kitchen and carry back coffee.</i>	<i>Trade one day of receptionist lunch coverage with someone who can make and carry coffee.</i>

Look over the list of accommodations you have generated and analyze them further. Would any of these accommodations increase your productivity and your value to your employer? Consider each accommodation in terms of its effectiveness for you as well as from the viewpoint of your employer. Take some time now to perform this analysis.

Accommodation	This accommodation will help me by:	This accommodation will help my employer by:
<i>Example: Headset for phone</i>	<i>Reduce fatigue caused by holding phone with head.</i>	<i>I will be able to answer more phone calls.</i>