



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. The six DVD

segments, covering the topics described above, are available online at <http://www.nationalmssociety.org/multimedia-library/webcasts--podcasts/career-crossroads/index.aspx>. 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 include the following:

- **National MS Society brochure *ADA & People with MS***
<http://www.nationalmssociety.org/multimedia-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.
- **Job Accommodation Network (JAN)** <http://www.jan.wvu.edu> and <http://www.jan.wvu.edu/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?

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://www.jan.wvu.edu/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/esa/whd/fmla/>
- <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 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**
<http://www.nationalmssociety.org/multimedia-library/webcasts-->

[podcasts/career-crossroads/index.aspx](http://www.nationalmssociety.org/podcasts/career-crossroads/index.aspx) 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://www.jan.wvu.edu/>
1-800-526-7234
- **JAN publication specifically addressing accommodating MS in the workplace**, <http://www.jan.wvu.edu/media/MS.html> or <http://www.jan.wvu.edu/media/MS.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)** <http://www.jan.wvu.edu/EeGuide/> or <http://www.jan.wvu.edu/EeGuide/EeGuide.pdf>. Or, 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?** Review a sample request for a job accommodation. <http://www.jan.wvu.edu/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](http://www.napas.org/index.htm).
- 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://www.jan.wvu.edu/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://www.jan.wvu.edu>. JAN also has extensive information about self-employment and entrepreneurship. This information can be found at <http://www.jan.wvu.edu/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.disabilityinfo.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>.
- **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.

- **MSWorkplace** is a collaboration among the National MS Society, monster.com, Biogen Idec and Elan. Visit www.MSWorkplace.com to search for jobs, post your resume and view information about MS for employers.
- **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) that connects employers seeking quality employees with skilled job candidates. Visit www.earnworks.com or phone 1-866-327-6669.
- **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).



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.

Organize

- 1. Describe your issue or concern and your preferred solution to resolve 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: Create a summary statement.

It is important for me to continue working. In order 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 in order to continue working successfully.

Practice saying it.

- 2. List the pros and cons of taking steps toward self-advocacy. This includes identifying 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.

Table with 2 columns: Pros, Cons. Pros: Working brings in a paycheck and provides benefits to me and my family. Cons: 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? | National MS Society ADA, Win-Win Approach brochures, employment publications Job Accommodation Network (JAN) DBTAC (ADA&IT Technical Assistance 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? | 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? | 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? | Job Accommodation Network (JAN) U.S. Equal Employment Opportunity Commission (EEOC) National MS Society Local office of human relations/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. |

- 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.

- Brainstorm possible solutions to address your concern.

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

- Review your rights and responsibilities (*see #4 above*). Revisit question 6. Put a star next to your preferred solution(s), given your rights and responsibilities.
- 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 Relations |
| | | |

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

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.

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 Relations Commission. I can do more research into my options under the ADA by calling JAN and my local DBTAC.

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

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 or not to proceed.

If the situation involves family, broadening the discussion to include a trusted counselor or clergy member may be useful.



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Analyzing the Effects of MS on Work

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.

| My MS Symptoms | Rate the Impact | Examples of Impact |
|--------------------------------|-----------------|--|
| EXAMPLE – Fatigue in afternoon | 6 | Almost fall asleep at desk, have trouble focusing in afternoon meeting, error rate higher in afternoon |
| | | |
| | | |
| | | |
| | | |
| | | |

Taken from **Career Crossroads: Employment and MS**, National Multiple Sclerosis Society, 1-800-344-4867, www.nationalMSSociety.org.



Disclosure Decision Worksheet

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

| Why are you telling? | |
|-----------------------------------|--------------------------------|
| Anticipated Positive Consequences | Possible Negative Consequences |
| | |

| Whom are you telling? | |
|-----------------------------------|--------------------------------|
| Anticipated Positive Consequences | Possible Negative Consequences |
| | |

| How much are you telling? | |
|-----------------------------------|--------------------------------|
| Anticipated Positive Consequences | Possible Negative Consequences |
| | |

Bottom Line: Based on all of the above, the best alternative for me is:



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Employment Disclosure Worksheet For Self Advocacy

First of all, remember that disclosure is a highly individual decision. The Fall 2004 issue of *InsideMS* included a pop quiz, "Should You Tell Your Boss?" You may find the following questions from this quiz helpful in your decision whether or not 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.

Take the time now to determine your feelings as to whether or not you want to disclose to your current employer, a new supervisor, or new co-worker. Answering the following questions and 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 some 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).

Taken from **Career Crossroads: Employment and MS**, National Multiple Sclerosis Society, 1-800-344-4867, www.nationalMSSociety.org.



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Analyzing Your Need for Reasonable Accommodations 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.

| My job functions | Essential/ Non-essential | List specific MS symptoms that are affecting each job function. | Possible accommodations/other tasks |
|--|-----------------------------|---|--|
| EXAMPLE: Taking turns twice a week making coffee | Non-essential | Can't walk all the way to the kitchen and carry back coffee. | Trade one day of receptionist lunch coverage with someone who can make and carry coffee. |
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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: |
|-----------------------------------|---|---|
| EXAMPLE: Headset for phone | Reduce fatigue caused by holding phone with head. | I will be able to answer more phone calls. |
| | | |
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Taken from **Career Crossroads: Employment and MS**, National Multiple Sclerosis Society, 1-800-344-4867, www.nationalMSSociety.org.



National
Multiple Sclerosis
Society

What is Self Advocacy?

Self advocacy means speaking up for yourself. It refers to your ability to effectively communicate an interest, desire, need, or right — and negotiate to get it. It also means making informed decisions and taking responsibility for them. Effective self-advocates understand individual strengths and needs, identify personal goals, and recognize legal rights and responsibilities. The impact of effective self advocacy reaches far beyond the individual; concrete changes and decision-makers with enlightened perspectives can have a lasting impact on many others as well.

Self advocacy throughout life

This self advocacy guide discusses effective practices and communication styles for you to best represent yourself and your interests throughout life. Whether you or a loved one lives with multiple sclerosis, effective self advocacy is a life skill sure to improve outcomes, regardless of the need or situation. The self advocacy worksheet that accompanies this material is a practical tool to help you turn this information into real-world results.

Effective practices for self advocacy:

- ❖ Assess your situation. **Describe your limitations, your unique needs or your special concerns.**
- ❖ Consider and evaluate useful aids, accommodations or solutions for your situation. **Define what will meet your needs or address your concerns.** Identify your desired outcome.
- ❖ Research and know your legal rights related to the situation. **Summarize your points for discussion.** Rehearse with a family member or friend.
- ❖ Identify those who may have the authority to meet your needs. **Contact or visit the front line for customer service first.** Invite a friend or family member to join you for an in-person meeting.
- ❖ **Anticipate the reaction to your request.** Consider potential reasons for resistance to your request. Try to understand the other person's point of view.
- ❖ **Be concise.** Describe your unique needs or your special concerns.
- ❖ **Remain mindful of your desired outcome.** Stay open to all potential avenues to achieve it.

- ❖ Be honest. Share any positive aspects about your situation or your circumstances which you benefit from, appreciate or value. **Cultivating empathetic allies can only help your cause.**
- ❖ **Document your discussion.** Record the name of the person you speak with, as well as the date, time, key points and necessary follow-up.
- ❖ **Be persistent.** Identify the next level of authority if you are unable to address your unique needs or concerns during negotiations.
- ❖ **Request the decision-maker's response in writing.** Know your appeal rights.
- ❖ **Be organized in your approach.** Use registered mail, keep copies of documents, track dates, take detailed notes, use checklists and make use of any organizational tools or systems that will help you to be more effective.

Effective communication styles for self advocacy:

- ❖ **Always tailor your style and message to the perspectives of your audience.**
- ❖ **Exhibit self-confidence.** Communicate with conviction. Comprehend the facts.
- ❖ Listen and ask questions. **Seek solutions in a collaborative fashion.**
- ❖ Conduct a dialogue. **Be conversational.** Pause to hear the other person's point of view. Maintain eye contact and a receptive facial expression.
- ❖ Exhibit respect. **Be assertive, but not aggressive.** Avoid accusations, judgments and exaggerations. Attempt to minimize displays of emotion.
- ❖ Dress appropriately for the situation. Thank the person for their time. **Be polite.**
- ❖ If communicating via letter or e-mail, **use standard spelling and grammar.** Avoid slang. Proofread.
- ❖ **Establish mutual accountability.** Determine the next steps, who will complete them, and target dates.



Prepare & take action

This worksheet is designed for you to organize your thoughts and actions for effective self advocacy in various life settings. Review the entire worksheet before you begin but respond only to what is relevant to your circumstances.

Organize

- 1. Describe your issue or concern and your preferred solution to resolve it.

Cause: Describe the cause of your unique situation.

Effect: Summarize what you aim to change. Describe your key intent.

Issue: Create a summary statement:

Because: _____, I need or I want _____.

Practice saying it.

- 2. List the pros and cons of taking steps toward self advocacy. This includes identifying 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.

Table with 2 columns: Pros, Cons and 3 empty rows.

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

| Question | Reference, Resource or Contact Information | Outcome |
|----------|--|---------|
| | | |
| | | |
| | | |
| | | |

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

| My Rights | My Responsibilities |
|-----------|---------------------|
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- 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.
- Brainstorm possible solutions to address your concern.
- Review your rights and responsibilities (see 4 above). Revisit question 6. Put a star next to your preferred solution(s), given your rights and responsibilities.
- Anticipate objections or resistance to your preferred solution(s). Summarize your responses to the likely arguments against your request. Refer to information you can use to support your argument.

| Objection | Response | Reference or Resource <i>in support of your response</i> |
|-----------|----------|---|
| | | |
| | | |
| | | |

9. Establish a fall-back position or “bottom line” if your preferred solution is not adopted. What are you are willing to settle for?

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.

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

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 or not to proceed.

If the situation involves family, broadening the discussion to include a trusted counselor or clergy member may be useful.