



National
Multiple Sclerosis
Society

Social Security Disability Resources For Self Advocacy

Introduction

This guide is intended to help people with multiple sclerosis (MS) advocate effectively to obtain the Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits to which they are entitled.

To advocate successfully, you must show that your MS causes disability severe enough to prevent you from working. You must be able to present yourself not as the competent worker you once were but as a person who can no longer perform substantial gainful activity, as that term is defined by the Social Security Administration (SSA).

The National MS Society has prepared a detailed guidebook to help you decide whether applying for disability benefits is right for you and to help you navigate the complex application process. It includes information, helpful hints and useful worksheets. Entitled **Social Security Disability Benefits, A Guide for People Living with Multiple Sclerosis**, it is available online or from your chapter.

Available at: <http://www.nationalmssociety.org/government-affairs-and-advocacy/government-programs/social-security-disability/download.aspx?id=186> or call 1-800-344-4867.

Before you meet with your doctor or an SSA representative, understand the offered benefit, what lies ahead and what information you will need. Learn the vocabulary. The more you know, the easier it will be to state your case.

Do your research

- Use the National MS Society's Social Security Disability Benefits, A Guide for People Living with Multiple Sclerosis ("SSD Guide") to guide you through your course of action:
<http://www.nationalmssociety.org/government-affairs-and-advocacy/government-programs/social-security-disability/download.aspx?id=186>
- Find out what types of benefits are available to you from the government:
<http://www.socialsecurity.gov/dibplan>
- Find out what types of benefits are available from your employer.
- Learn the criteria for qualifying for these benefits. Which criteria apply to you? The National MS Society SSD Guide will take you step by step through this process.
- Assess how much you would receive in benefits. Check the statement sent to you by SSA or use SSA's adult disability benefits calculator:
www.socialsecurity.gov/planners/calculators.htm

Get organized before you apply.

- Find assistance if you need it.
- Determine what information you will need to apply.
- Begin to collect the information you will need for your application, and keep all materials in a folder.
- Keep a detailed journal. Information available at: <http://www.nationalmssociety.org/government-affairs-and-advocacy/government-programs/social-security-disability/download.aspx?id=186> See pp. 11-13.

Meet with your doctor.

Once you have decided to apply for disability benefits and done your homework, make an appointment with your doctor to discuss your application. You will need your doctor's support.

What to say to your doctor

- Explain that you are applying for Social Security disability benefits because your symptoms prevent you from working. Tell your doctor everything that prevents you from working — every debilitating symptom. Don't be brave, don't put your best foot forward; you can tell your doctor things you would not tell your best friend.
- Since your doctor will be required to provide evidence of your disability, the more you tell him that he enters into his records, the better your chances are for being approved.
- Bring the National MS Society's guidebook, your folder of important documents, your journal, and any other relevant information with you to the appointment.
- If your doctor is not familiar with Social Security process, explain that medical evidence must substantiate your impairments and your inability to work. Give her a copy of the National MS Society's **SSD Guide for Professionals** available at: <http://www.nationalmssociety.org/government-affairs-and-advocacy/government-programs/social-security-disability/download.aspx?id=514>. At a minimum, provide your doctor with the sample letter and guidelines in your SSD Guide. If your doctor does not have a copy of the criteria for evaluating impairments caused by MS used by the SSA, give her a copy from either one of the National MS Society's guidebooks.
- At every visit, brief your doctor(s) on all of your medical issues or disabilities.

Prepare your application

You can begin the application process online or by calling Social Security at 1-800-772-1213. Download or ask for a starter kit to help you get ready for your disability interview or online application.

http://www.socialsecurity.gov/disability/disability_starter_kits.htm

- Review the MS Listing and Criteria Reference in your SSD Guide (Appendix E); refer to this information but describe your MS symptoms in your own words.
- Use the three worksheets in your SSD Guide to organize your medical history, describe your past jobs and articulate how your MS impairs your ability to work.
- Applying in person or by telephone has the advantage of giving you a direct contact person for your questions. Applying online allows you to work at your own pace.

How to handle an in-person interview

- Prepare by reviewing all the materials and worksheets you have assembled. Use this material and your journal to explain how your MS symptoms prevent you from working.
- In your journal, write down what you would like to say in the interview. As set out in the SSD Guide, main points could include:
 - I have a severe disability (or several severe disabilities) due to MS.
 - Due to this disability (these disabilities), I cannot work at all.
 - MS is an impairment that is on the Social Security Listing of Impairments.
 - I have a severe disability covered in at least one of the four MS Listing Criteria.
- Practice your speech until you feel comfortable talking about your personal circumstances.
- Be sure to bring all necessary materials with you. Make copies of everything you will submit to the SSA. Keep your originals.
- Ask for your SSA interviewer's contact information so that you can follow up later.

Find assistance if you need it

If the National MS Society guidebook does not give you enough confidence to tackle the initial application or interview process by yourself, or if your symptoms interfere with your ability to complete the tasks you need to do, consider ways to get the help you need to succeed.

Perhaps a friend or family member can help you collect and organize your work history and medical information. Ask someone to listen to you practice for your interview.

Your area National MS Society chapter may be able to recommend free professional assistance.

There is always the option of hiring an attorney or skilled representative to see you through the process; they will only be paid if your application is granted. Your chapter may help you identify lawyers familiar with MS or you may contact the National Organization for Social Security Representatives (NOSSCR). (See Resources below.)

If your application is denied, appeal. DO NOT ALLOW YOUR TIME TO EXPIRE OR YOU WILL BE BACK TO SQUARE ONE.

- Follow instructions in the SSA letter to appeal within 60 days.
- It is helpful to submit additional information to strengthen your case.
- Your chances of success are better at a hearing if you have a skilled representative presenting your case. If you hire a representative who charges for his services, he will only collect a fee if he obtains benefits for you. (See Resources below.)

Resources

1. The National MS Society has various resources to assist in this process. Call your chapter or visit the National MS Society Web site and begin your research here:

<http://www.nationalmssociety.org/government-affairs-and-advocacy/government-programs/social-security-disability/index.aspx>

- For you: **Social Security Disability Benefits — A Guide for People Living with Multiple Sclerosis**. Available in hard copy by calling your chapter at 1-800-344-4867 or online at <http://www.nationalmssociety.org/government-affairs-and-advocacy/government-programs/social-security-disability/download.aspx?id=186>.
- For your doctor: **Social Security Disability Benefits for People Living with Multiple Sclerosis — A Guide for Professionals**. Available in hard copy by calling your chapter at 1-800-344-4867 or online at <http://www.nationalmssociety.org/government-affairs-and-advocacy/government-programs/social-security-disability/download.aspx?id=514>.

2. General text on SSDI: **Nolo's Guide to Social Security Disability: Getting and Keeping Your Benefits** by [David Morton III, M. D.](#) (\$29.99).

<http://search.barnesandnoble.com/Nolos-Guide-to-Social-Security-Disability/David-Morton/e/9781413307641>

3. Social Security Administration Web site: Link to:

<http://www.socialsecurity.gov/disability> and <http://www.socialsecurity.gov/ssi>

4. Contacts for finding professional assistance:

- Contact your chapter at 1-800-344-4867 for referrals to attorneys, legal services or other programs that provide assistance to people applying for public benefits.
- Ask your doctor about attorneys who have successfully represented other patients.
- Contact the National Organization for Social Security Claimants' Representatives: www.nosscr.org/refer.html or 1-800-431-2804.
- For more information about representatives and fees, visit: www.socialsecurity.gov/pubs/10075.pdf and www.ssa.gov/thirdparties.htm.



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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.



Self Advocacy Worksheet

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.

Pros	Cons

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

- 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.