



National
Multiple Sclerosis
Society

Self Advocacy for Medical Care and Long Term Care

Introduction

This guide is intended to help people with multiple sclerosis engage in self advocacy to better understand and guide their medical care, and, as necessary, manage their long-term care. It offers an overview of Web sites, resources and information related to these topics for the self-advocate's research purposes. The question-and-answer format was designed to help you navigate through these difficult topics. You will also see some general self advocacy questions without answers that are intended to help you start thinking about your current situation.

The National MS Society's Self Advocacy Worksheet (available at <http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/download.aspx?id=8130>) complements this guide. It is intended to assist you in planning your course of action. Refer to it to assess your circumstances, concerns or needs, and identify your aims or goals regarding self advocacy. You can also review sample case studies applied to this worksheet. The example for medical is available at <http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-for-medica-care-and-LTC/download.aspx?id=8149>. The example for long-term care can be accessed at <http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-for-medica-care-and-LTC/download.aspx?id=8148>.

To discuss any questions about this material or to request a printed copy of any of the National MS Society Web pages or publications referred to in this guide, call an MS Navigator® at 1-800-344-4867.

Medical Care

Whether you are in the pre-diagnosis stage or have advanced MS, you may have questions that need to be answered in order to feel comfortable talking about symptoms or new complications in your disease course with your treating medical professional or family members. Please review the information below to help you get ready to advocate for your own medical care.

Pre-diagnosis

If you suspect that you may have MS, or are experiencing symptoms that you have questions about, please read the following answers to some basic questions about MS.

- What is MS?
Multiple sclerosis (MS) is a disease that attacks the central nervous system (CNS), which is made up of the brain, spinal cord and optic nerves. The

progress, severity and specific symptoms of MS are unpredictable and vary from one person to another.

- What causes MS?

While the cause (etiology) of MS is still not known, scientists believe that a combination of several factors may be involved. Studies are ongoing in the areas of immunology (the science of the body's immune system), epidemiology (looking at patterns of disease in the population), and genetics in an effort to answer this important question.

- Who gets MS?

In the United States today, there are approximately 400,000 people with MS – with 200 more diagnosed every week. Worldwide, MS is thought to affect more than 2.1 million people. While the disease is not contagious or directly inherited, epidemiologists – scientists who study patterns of disease – have identified factors in the distribution of MS around the world that may eventually help determine what causes the disease. These factors include gender, genetics, age, geography and ethnic background.

- What are the symptoms?

Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision.

- How is MS diagnosed?

There are several tests, strategies and exams that are done in combination to diagnose MS. One test alone is not enough to diagnose MS. The main diagnostic tools are MRI, spinal tap, visual evoked potential, blood tests to rule out other diseases, and an extensive medical history and exam.

Pre-Diagnosis resources:

What is MS? National MS Society Web site

<http://www.nationalmssociety.org/about-multiple-sclerosis/what-is-ms/index.aspx>

What Causes MS? National MS Society Web site

<http://www.nationalmssociety.org/about-multiple-sclerosis/what-causes-ms/index.aspx>

Who Gets MS? National MS Society Web site

<http://www.nationalmssociety.org/about-multiple-sclerosis/who-gets-ms/index.aspx>

Symptoms: National MS Society Web site

<http://www.nationalmssociety.org/about-multiple-sclerosis/symptoms/index.aspx>

Diagnosing MS: National MS Society Web site

<http://www.nationalmssociety.org/about-multiple-sclerosis/diagnosing-ms/index.aspx>

Frequently Asked Questions About Multiple Sclerosis: National MS Society Web site

<http://www.nationalmssociety.org/about-multiple-sclerosis/FAQs-about-MS/index.aspx>

Do I have MS? National MS Society Web site

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/do-i-have-ms/index.aspx>

Clinically Isolated Syndrome (CIS): National MS Society Web site

<http://www.nationalmssociety.org/about-multiple-sclerosis/diagnosing-ms/cis/index.aspx>

MS diagnosis

This section is intended to assist you once you have a confirmed MS diagnosis. It includes information about health care teams for MS, how to choose health care professionals, treatment for MS, alternative therapy and clinical trials. You will also notice lists of questions to ask yourself regarding your health care. These questions are intended to help you self-advocate to ensure that the care that you are receiving for your MS is the best care possible. The questions are also intended to help you evaluate if a change needs to be made in your current health care team or if you need to speak with your treating physicians regarding your care.

- Who should be on my health care team?

The health professionals who are likely to be involved with your care at some point over the course of the disease may include a family physician, neurologist, neuropsychologist, nurse, occupational therapist, orthotist, physiatrist, physical therapist, speech/language pathologist, and urologist.

- How well do you work with your doctors and other members of your MS health care team?
- Do you understand the role that each member of your health care team plays in your MS care?
- Do you feel respected and that you are being listened to? Would your caregiver agree?
- How do you locate doctors with MS expertise?

If you need a referral to an MS clinic or a neurologist with experience with MS, please call an MS Navigator® at the phone number above or refer to the Web site below.

MS diagnosis resources:

Team of Professionals: National MS Society Web site

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/team-of-ms-professionals/index.aspx>

The Family's Relationship with the Physician and Health Care Team: **MS: A Guide for Families** by Dr. Rosalind C. Kalb, PhD: Information available at

<http://www.nationalmssociety.org/multimedia-library/books/a-guide-for-families/index.aspx>

Primary Care in MS: National MS Society Web site

<http://www.nationalmssociety.org/for-professionals/healthcare-professionals/publications/clinical-bulletins/download.aspx?id=3689>

Making the Most of Your Doctor Visits: National MS Society Web site

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/doctors-visit/index.aspx>

Resources for MS Physicians:

Treatment Locations by State: National MS Society Web site

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/treatment-locations/index.aspx>

Choosing the Right Health Care Providers: National MS Society Web site

<http://www.nationalmssociety.org/download.aspx?id=25>

How is MS treated?

Although there is still no cure for MS, effective strategies are available to modify the disease course, treat exacerbations (also called attacks, relapses or flare-ups), manage symptoms, improve function and safety, and provide emotional support. In combination, these treatments enhance the quality of life for people living with MS.

- Are you following all of your doctor's advice?
- Is there anything about your MS treatment that displeases you? Are you sharing that with your treating physician? Are you discussing treatment goals?
- Emotional concerns?
- Complementary and Alternative Therapies?

- Do you know why your doctor has prescribed certain medications — including disease-modifying and symptom management drugs?

Disease-modifying therapies can reduce disease activity and disease progression for many individuals with relapsing forms of MS, including those with secondary-progressive disease who continue to have relapses.

Treatment resources:

MS and Your Emotions: National MS Society Web site
<http://www.nationalmssociety.org/download.aspx?id=151>

Complementary and Alternative Medicine: National MS Society Web site
<http://www.nationalmssociety.org/about-multiple-sclerosis/treatments/complementary--alternative-medicine/index.aspx>

Treatments: National MS Society Web site
<http://www.nationalmssociety.org/about-multiple-sclerosis/treatments/index.aspx>

The Disease-Modifying Drugs: National MS Society Web site
<http://www.nationalmssociety.org/aboutmultiplesclerosis/treatments/download.aspx?id=45>

Advanced MS

Multiple sclerosis is a [progressive disease](#) for which no cure has yet been found. Although we have treatments to manage the disease course, they are only partially effective, which means that some people's MS will worsen in spite of everything they and their doctors do to try and prevent it.

Many people ask themselves: Why did this happen? Did I choose the wrong doctor or the wrong medication? Did I follow the wrong diet or the wrong exercise program? Did I get too stressed out at my job? But the fact is, MS progresses because that is the natural course of the disease.

While researchers are working to identify new and better strategies to stop that progression, people whose MS has become more disabling — and their family members and friends — need information about how to manage the challenges they face.

Advanced MS Resources:

Living with Advanced MS: National MS Society Web site
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/living-with-advanced-ms/index.aspx>

Caring for Loved Ones with Advanced MS: A Guide for Families: National MS Society Web site

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/living-with-advanced-ms/download.aspx?id=789>

Managing Progressive MS: National MS Society Web site

<http://www.nationalmssociety.org/download.aspx?id=314>

So You Have Progressive MS: National MS Society Web site

<http://www.nationalmssociety.org/download.aspx?id=316>

My MS, My Way: National MS Society Web site

<http://www.mymmsmyway.com/>

Living Wills: Protecting Your Medical Choices: National MS Society Web site

<http://www.nationalmssociety.org/multimedialibrary/momentummagazine/momentum-summer-08/download.aspx?id=1064>

Long-Term Care

The progress, severity and specific symptoms of multiple sclerosis in any one person cannot yet be predicted. Nearly a quarter of individuals living with MS will require long-term care support and services at some point during the course of the disease. The National Multiple Sclerosis Society is dedicated to helping people living with MS and their families secure those critical services.

- What is long-term care?

The phrase “long-term care” refers to all the services that people with an illness or disability might need to help them in performing activities of daily life, such as dressing, showering, preparing meals, managing their home and so forth. Long-term care encompasses a wide range of services, including housekeeping, personal assistance, adult day health care, respite care, support for caregivers, community housing options and nursing home care.

- Do I need long-term care?

This decision needs to be made by you, your family and your health care team.

- How do I pay for long-term care?

Shopping around for private long-term care insurance after a diagnosis is your best bet in finding an insurer. Please note that relatively few long-term care insurers will sell to people with MS. Those that do may not widely advertise and may accept people on a case by case basis.

- Do you have personal insurance that will pay for long-term care?

You need to check with your private insurance company to see if they cover the expense for long-term care. Please check any and all policies that you

hold including all long term-care policies — private and through your employer.

- How much care do I need?

This is a question that you need to discuss with your doctor. Your treating physician and your care team can make the correct recommendations as far as your level of care, and write your recommended care plan.

Long-term care resources:

Long-Term Care: Support and Services Background: National MS Society Web site

<http://www.nationalmssociety.org/download.aspx?id=206>

MS: The Questions You Have, the Answers You Need by Dr. Rosalind C. Kalb, Chapter 16: Information available at

<http://www.nationalmssociety.org/multimedia-library/books/the-questions-you-have/index.aspx>

Opening Doors: The Palliative Care Continuum in MS: National MS Society Web site

<http://www.nationalmssociety.org/for-professionals/healthcare-professionals/publications/clinical-bulletins/download.aspx?id=1027>

American Health Care Association

1201 L Street, NW

Washington, DC 20005

1-202-842-4444

<http://www.longtermcareliving.com/>

Adapting: Financial Planning for a Life with MS: National MS Society Web site

<http://www.nationalmssociety.org/download.aspx?id=11>

Talking About Life Planning: National MS Society Web site

<http://www.nationalmssociety.org/for-professionals/healthcare-professionals/publications/download.aspx?id=183>

The Long Term Care Needs of People with MS: National MS Society Web site

<http://www.nationalmssociety.org/download.aspx?id=222>

Shopping for Life, Disability and Long-Term Care Insurance: National MS Society Web site

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/other-insurance/shopping-for-insurance/index.aspx>

Plan Smart for the Long Term: Medicaid Changes You Should Know: National MS Society Web site

<http://www.nationalmssociety.org/multimedia-library/momentum-magazine/back-issues/insidems-feb-mar-2007/download.aspx?id=119>

- What is assisted living?

Please see document below, "Assisted Living for Individuals with MS" or visit

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=522>

- What is the difference between assisted living and skilled nursing facilities?

Assisted living is intended to provide a residential environment and resident-centered services that foster residents' quality of life, privacy, choice, dignity and independence. It is intended to provide quality services, individualized for residents and developed collaboratively with them, to support the resident's decision making to the maximum extent possible.

Skilled Nursing Facilities offer a higher level of care as well as 24 hour skilled nursing services if necessary. Skilled nursing facilities are expected to meet a client's daily needs while trying to maintain the client's independence and physical well being.

- Can I stay in my home with a caregiver?

Please review options for in-home care and caregiver resources below.

Assisted living/Skilled nursing facility/In-home resources:

Assisted Living for Individuals with MS: Guidelines and Recommendations for Quality Care: National MS Society Web site. For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=522>

Assisted Living Federation of America

1650 King Street, Suite 602

Alexandria, VA 22314

1-703-894-1805

<http://www.alfa.org/i4a/pages/index.cfm?pageid=3278>

Nursing Home Care of Individuals with MS: Guidelines and Recommendations for Quality Care: National MS Society Web site. For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=523>

Centers for Medicare and Medicaid Services: Certification and Compliance,
Nursing Homes

1-800-MEDICARE (1-800-633-4227)

http://www.cms.hhs.gov/CertificationandCompliance/12_NHs.asp#TopOfPage

<http://www.medicare.gov/Publications/Pubs/pdf/02174.pdf>

Centers for Medicare & Medicaid Services

7500 Security Boulevard

Baltimore, MD 21244-1850

1-800-MEDICARE (1-800-633-4227)

<http://www.medicare.gov/NHCompare/Include/DataSection/Questions/SearchCriteria.asp?version=default&browser=IE%7C6%7CWinXP&language=English&defaultstatus=0&pagelist=Home&CookiesEnabledStatus=True>

<http://www.medicare.gov/NHCompare/Include/DataSection/Questions/SearchCriteria.asp?version=default&browser=IE%7C6%7CWinXP&language=English&defaultstatus=0&pagelist=Home&CookiesEnabledStatus=True>

Great Places

<http://www.greatplacesinc.com/>

A Place for Mom

221 First Ave. West, Suite 350

Seattle, WA 98119-4285

1-206-285-4666

1-877-MOM-DAD9 (1-877-666-3239)

www.aplaceformom.com

Caring for Loved Ones with Advanced MS: A Guide for Families: National MS Society Web site

<http://www.nationalmssociety.org/download.aspx?id=789>

The Lifespan Respite Care Act Position: National MS Society Web site

<http://www.nationalmssociety.org/download.aspx?id=208>

Serving Individuals with MS in the Home: Guidelines and Recommendations for Home Care Providers and Personal Care Assistants: National MS Society Web site

<http://www.nationalmssociety.org/download.aspx?id=1015>

A Guide for Caregivers: Managing Major Changes: National MS Society Web site

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=155>

MS Basic Fact Series: Hiring Help at Home: National MS Society Web site

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=313>



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Self Advocacy Worksheet (Sample – Medical)

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.

I am in the process of getting a diagnosis and it's taking a long time. I'd like to find a doctor who can speed up the process.

Cause: Describe the cause of your unique situation.

I am worried that the longer I go without a diagnosis, the more the disease may progress. My maternal aunt died of complications from MS and I am scared I will too. Until I have answers, I cannot move forward to make decisions regarding my health.

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

Because I am anxious to move on with my life, I'd like to get a good doctor to give me a diagnosis of MS. I need a physician who will listen to me, who understands this disease and is aggressive about treating my illness and symptoms.

Issue: Create a summary statement.

I will get a diagnosis quickly through working with a physician who has expertise with MS.

Because: Because I am anxious to move on with my life, I'd like to get a good doctor to give me a diagnosis of MS.

I need or I want: I need a physician who will listen to me, who understands this disease and is aggressive about treating my illness and symptoms.

Practice saying it.

- 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
I am still in good health.	I am scared about what a diagnosis means.
I have a strong family.	I don't want my family to worry.
I have health insurance.	I do not want to feel sick.

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

Question	Reference, Resource or Contact Information	Outcome
How is MS diagnosed?	National MS Society 1-800-344-4867	The specialist I spoke with directed me to information about the diagnostic process: Diagnosing MS: National MS Society Web site — http://www.nationalmssociety.org/about-multiple-sclerosis/diagnosing-ms/index.aspx
Who are the best doctors to diagnose and treat MS?	National MS Society 1-800-344-4867	The specialists I spoke with told me about a brochure to help me make good choices when considering physicians to diagnose and treat my MS: Choosing the Right Health Care Providers: National MS Society Web site http://www.nationalmssociety.org/download.aspx?id=25
How can I make sure the doctor listens to my questions before	National MS Society 1-800-344-4867	The specialist recommended a brochure to help answer my question: Making the Most of Your Doctor Visits: National MS Society Web site http://www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/doctors-visit/index.aspx

rushing me out of the office?		

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

My Rights	My Responsibilities
I have a right to a speedy diagnosis.	Pursue a doctor who has experience.
I have a right to medications.	Read the information about each of the disease-modifying drugs to make an educated choice with my doctor.
I have a right to ask my doctor questions.	Prepare for the visit by writing the questions I have down on paper so I don't forget.

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 guess that would be me and my doctor. After my visit next month, I hope to have not only a diagnosis, but a plan for taking care of my health.

6. Brainstorm possible solutions to address your concern.

I will be prepared with questions for my visit and have read all of the information about making the most of my doctor's visits.

7. Review your rights and responsibilities (see #4 above). Revisit question six. 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>
The doctor asks me to repeat all the testing I've already done.	I will release all medical records and contact my insurance company.	This suggestion was made by the specialist I spoke to at the Society.
I cannot see a doctor with MS expertise for 6 months.	Find out if the doctor has extra clinic hours or if he/she supervises residents whom I can see sooner.	Same as above

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

I've already spoken to another neurologist, so I'm not willing to settle for less than an MS expert or resident supervised by an MS expert.

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.

I will ask to be put on a wait list in case the doctor has a cancellation.

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.



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Self Advocacy Worksheet (Sample – Long Term Care)

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 need to consider means to pay for care in the future, if my disability progresses.

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

I will find a source of financial assistance to pay for my future health care at home.

Issue: Create a summary statement.

Because: I have multiple sclerosis, I must consider my potential future needs.

I need or I want: assistance paying for care on an ongoing basis if my disease continues to progress.

Practice saying it.

I will plan for my long-term care needs and find a means to pay for it. Being prepared is better than not planning ahead and then not having necessary resources.

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
I am independent.	I am scared.
I can care for myself.	I don't know what lies ahead.
I am strong.	I do not have a caretaker.

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
Is there insurance to help pay for home health care?	1-800-789-5191 www.aiplanners.com	Long-term care insurance
Are there other resources that may help with my long-term care planning?	1-800-344-4867	List of skilled nursing facilities in my area, http://www.nationalmssociety.org/download.aspx?id=11 http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=522 http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=523
A financial planner	Referral through the Nat'l MS Society	www.nationalmssociety.org 1-800-344-4867

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

My Rights	My Responsibilities
To Plan Ahead	To Plan
To Protect my Future	To Protect my Future

To Educate Myself

To Educate Myself

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.

No one has authority over my care at this point but me. If this ever changes, I will set up something legally, but at this time I see no reason to put something in place.

6. Brainstorm possible solutions to address your concern.

I need to find an insurance broker or other resource to help me find out if I am eligible for a long-term care insurance policy.

7. 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.

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

Objection	Response	Reference or Resource <i>in support of your response</i>
Will not sell long-term care insurance to me because of my MS	Are there any other insurers that will sell a LTC policy to someone with MS?	The National MS Society warned me that I might not be eligible for a LTC policy.

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

If I cannot get LTC insurance, I would probably try to hire someone to help me at home and pay for it myself, but could I afford that?

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.

I would need advice from an expert about the costs of this type of care, whether I have to sell my home, or ask for government help.

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

I am still hoping my disease will not progress to the point that I need someone to care for me.

I have learned that Medicare does not cover long term care, and I may not be able to buy long-term care insurance because of my MS.

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.



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.



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

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

My Rights	My Responsibilities

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.
6. Brainstorm possible solutions to address your concern.
7. 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.
8. 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.

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