



National  
Multiple Sclerosis  
Society

## Health Insurance, Appeals and Medicare Resources For Self Advocacy

### Introduction

This guide is intended to help people diagnosed with multiple sclerosis better self-advocate for access to health care coverage. It offers an overview of Web sites, resources and information helpful to those seeking coverage or assistance with coverage-related problems. The question and answer format was designed to help 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 (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/download.aspx?id=8130>) and a case sample of the worksheet in action (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-for-health-insurance-issues/download.aspx?id=8144>) complement this guide.

These are intended to assist you in planning your course of action as you seek coverage for your medical care. Reference them to assess your circumstances, concerns or needs and identify your aims or goals related to access and coverage for health care services.

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.

### No insurance

If you are currently without insurance, please review the information below. This information is intended to assist in a first step analysis of your current situation.

- Has there been a lapse in creditable insurance coverage? Creditable coverage gives you credit for the amount of time that you have been insured by one health plan and applies that coverage to the pre-existing exclusionary period of a new group health plan. You can not have a lapse in coverage of more than 63 days in order for coverage to be considered creditable. Have you been uninsured less than 63 days?
- Are you eligible for COBRA (Consolidated Omnibus Budget Reconciliation Act of 1986) benefits? If it has not been more than 60 days since losing your group health benefit, contact your previous employer's Human Resource Department and inquire about COBRA benefits.

- Does your spouse or partner's employer offer any group health insurance benefits? If you have recently lost your benefits you may be able to apply for a change of status enrollment period through your spouse or partner's employer. If there is not a change of status you can enroll in their benefits during the open enrollment season.
- Do you have a disability? Does a child under the age of 18 live in your home? If yes to either, Medicaid may be an option for insurance coverage. Medicaid is a low income and asset health resource. If you have a low income and are without health insurance, you can make an appointment with your local Medicaid office to explore any potential benefit options.
- Do you receive Social Security Disability Insurance (SSDI)? If so, for how long have you received SSDI? If you are receiving SSDI payments and it has been 24 months since you initially applied for SSDI, you are entitled to Medicare. Please contact the Social Security Administration at 1-800-772-1213 for further information.
- Does your state offer access to High Risk Insurance benefits? Some states offer group health insurance benefits as a way to continue coverage for people with pre-existing conditions. Please see information under the heading of High Risk Insurance below for further details.

Resources for the uninsured:

Health Insurance Info.net  
 Georgetown University Health Policy Institute  
<http://healthinsuranceinfo.net/index.htm>

Cover the Uninsured  
 1-877-655-CTUW (2889)  
[info@covertheuninsured.org](mailto:info@covertheuninsured.org)  
<http://covertheuninsured.org/stateguides/>

Insure Kids Now  
 1-877-543-7669  
<http://www.insurekidsnow.gov/>

U.S. Department of Health and Human Services  
 Health Resources and Services Administration  
 Hill-Burton Free and Reduced Cost Health Care  
 1-800-638-0742 (1-800-492-0359 in Maryland)  
<http://www.hrsa.gov/hillburton/hillburtonfacilities.htm>

Needy Meds, Inc.

A list of patient assistance programs for medications including MS disease-modifying drugs. Patient assistance programs can help pay for the cost of medications for people without insurance. Some programs may assist with insurance co-pays.

P.O. Box 219  
Gloucester, MA 01931  
[www.needymeds.org](http://www.needymeds.org)

### **Health Insurance Portability and Accountability Act (HIPAA)**

If you currently have health insurance coverage, consider the following questions:

- Are you afraid you are going to lose your coverage?
- Have you had a lapse in health insurance coverage of less or more than 63 days? In order to maintain HIPAA coverage the time elapsed between health policies can not be more than 63 days or the new group coverage provider can implement a pre-existing condition clause into their policy.
- Do you have an option for other health insurance benefits to maintain continuity of coverage: spousal coverage, new employer coverage, COBRA coverage, high risk insurance, Medicaid or Medicare?

HIPAA resource:

National MS Society Web page on HIPAA:

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

### **COBRA (Consolidated Omnibus Budget Reconciliation Act of 1986)**

COBRA is an extension of health benefits for groups of 20 or more. COBRA is triggered when someone loses their group health benefits for any reason other than loss of job for gross misconduct. With COBRA, the qualified beneficiary would be responsible for the entire cost of the COBRA plus a 2% surcharge.

If you are currently employed and receive health care benefits, consider the following questions:

- Does your employer offer health insurance and are there 20 or more employees in the business or if your employer has 19 or fewer employees, have you checked with the Department of Insurance regarding COBRA-like protections?
- Will your employer health benefits be ending and is the employer still in existence? If the employer is going out of business, COBRA is not an option.
- Are COBRA benefits an option? Was your employment terminated for gross misconduct?
- Do you have a disability determination through the Social Security Administration? If so, the length of your COBRA benefits can be extended for an extra 11 months if you prove to the COBRA administrator within the first 60 days of enrollment that you have a disability.

- Will you have a source of income to maintain COBRA benefits? COBRA benefits will cost what the employer was paying plus what the employee was paying plus a 2% surcharge.
- If you are currently on COBRA, when will it end? Can you apply for a state-sponsored high risk insurance pool? COBRA is normally 18 months, 29 months with a disability extension, or 36 months in the case of divorce, legal separation, or death of the previous employee.
- Do you have a human resources department? Are you comfortable speaking to, or have you spoken with, an HR representative about the possibility of COBRA and the potential costs?

COBRA resource:

National MS Society Web page on COBRA:

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

### **High Risk Insurance**

If you are about to lose your health insurance coverage, consider the following questions and your potential access to a High Risk Insurance Pool:

- Are you at risk of losing your group benefits because you are leaving your job, your spouse is leaving a job, you may get fired, or you intend to take Long Term Disability (LTD)?
- Are you about to lose your job, but you cannot afford COBRA?
- Are your COBRA benefits about to run out?
- Are you looking for a way to extend your continuous coverage while looking for another job or going through the Social Security Disability Insurance waiting period for Medicare?

In all of these instances, check to see if your state has a High Risk Pool as not all states have enacted legislation for High Risk Pools. In the majority of states you must maintain creditable coverage to have access to a High Risk Pool without a pre-existing condition exclusionary period. If you know that any of the situations above may occur, investigate what potential coverage may be available through your State High Risk Pool.

High Risk Pool resource:

National Association of State Comprehensive Health Insurance Plans

[http://www.naschip.org/states\\_pools.htm](http://www.naschip.org/states_pools.htm)

### **Individual Health Insurance**

Do you live in a guarantee issue state or are you eligible for HIPAA protection?

- Maine, Massachusetts, New York, New Jersey and Vermont are guarantee issue states as far as individual health insurance is concerned. Within the states above, individual health insurance providers must sell to people regardless of their health status and/or any pre-existing conditions. In Michigan and Pennsylvania, Blue Cross/Blue Shield is the only guarantee issue provider regardless of health status for individual providers.

If you live in the U.S. and are HIPAA eligible, you are guaranteed the right to buy individual health coverage of some kind with no pre-existing condition exclusionary period. To be HIPAA eligible, you must meet all of the following guidelines:

- You must have had 18 months of continuous creditable coverage, *at least the last day of which was under a group health plan.*
- You must have used up any COBRA or state continuation coverage for which you were eligible.
- You must not be eligible for Medicare, Medicaid, or a group health plan.
- You must not have health insurance. (Note, however, if you know your group coverage is about to end, you can apply for coverage for which you *will* be HIPAA eligible.)
- You must apply for health insurance for which you are HIPAA eligible within 63 days of losing your prior coverage.

Your HIPAA eligible status ends as soon as you enroll in an individual health insurance policy, because the last day of your continuous health coverage must have been in a group plan. You can become HIPAA eligible again by maintaining continuous coverage and rejoining a group health plan (including a state offered high risk pool). ([www.healthinsuranceinfo.net](http://www.healthinsuranceinfo.net))

## Medicare

Consider the following questions and resources regarding Medicare eligibility.

- Are you over the age of 65, or do you have End Stage Renal Disease (ESRD) or Amyotrophic Lateral Sclerosis (ALS/Lou Gehrig's Disease)? If yes, you automatically qualify for Medicare.
- Are you receiving SSDI benefits? Medicare benefits start after SSDI has been awarded for 24 months (backdated to the date of your SSDI application).

Medicare resources:

National MS Society Web page on FAQ about Medicare:

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/medicare/faqs-about-medicare/index.aspx>

Centers for Medicare & Medicaid Services  
7500 Security Boulevard  
Baltimore, MD 21244-1850  
1-800-MEDICARE (1-800-633-4227)  
[www.medicare.gov](http://www.medicare.gov)

### **Medicare Part D**

If you have Medicare Part A or B, Medicare Part D is an option for prescription drug coverage.

Consider the following questions regarding your potential eligibility:

- Do you have Medicare A or B?
- Have you applied for Medicare Part D?
- Have you applied for Medicaid as a subsidy?
- Have you applied for the extra help program through the SSA that would assist with the premium, deductible, co-pays and donut hole of Medicare Part D?
- Have you applied for the Medicare Savings Program through your local Medicaid office? It can assist with Medicare Part A and B expenses.
- Have you applied for your State Patient Assistance Program, which may offer assistance to help with the out of pocket cost of Medicare Part D?
- Have you called the patient assistance program that covers your medication or disease-modifying drug to help with the expense of your disease modifying drug?

Medicare resources to help with out of pocket costs:

Medicaid - State by State Descriptions and Plans  
<http://www.colorado2.com/medicaid/states.html>

Social Security Administration  
Help with Medicare Prescription Drug Plan Costs  
1-800-772-1213  
<https://s044a90.ssa.gov/apps6z/i1020/main.html>

State Patient Assistance Programs-Medicare Interactive  
Medicare Rights Center  
1224 M Street NW  
Suite 100  
Washington, DC 20005  
Phone: 202.637.0961  
[http://www.medicareinteractive.org/ext\\_url.php?url=http://www.medicareinteractive.org/uploadedDocuments/mi\\_extra/spap\\_chart.html](http://www.medicareinteractive.org/ext_url.php?url=http://www.medicareinteractive.org/uploadedDocuments/mi_extra/spap_chart.html)

Medicare Savings Plan

Assistance with the Cost of Medicare Part A and B  
1-800-772-1213 or contact your local Medicaid office  
<http://www.medicare.gov/Publications/Pubs/pdf/10126.pdf>  
[http://www.medicareinteractive.org/ext\\_url.php?url=http://www.medicareinteractive.org/uploadedDocuments/mi\\_extra/msp\\_chart.html](http://www.medicareinteractive.org/ext_url.php?url=http://www.medicareinteractive.org/uploadedDocuments/mi_extra/msp_chart.html)

National MS Society Web page on Financial Assistance for Medicare Part D Plans  
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/medicare/medicare-prescription-drug-plans/financial-assistance/index.aspx>

## **Medicaid**

If you currently have no medical insurance, consider the following questions regarding Medicaid:

- Are you able to obtain and afford insurance through an employer, spouse, Medicare, COBRA, etc.?
- What is your income? Medicaid eligibility is different state by state. Eligibility is based on the Federal Poverty Guidelines.
- How many people are in your household? Medicaid also takes into consideration how many people are in your household when determining income.
- Do you have children under the age of 18? Children under the age of 18 are considered when determining eligibility.
- Do you have a disability classification from the SSA? A disability classification from the SSA can assist in eligibility for Medicaid.
- Are you currently working, but slightly over the Medicaid guideline? Programs like the Medicaid Buy-In Program may qualify you for Medicaid if you are over the income guidelines for Medicaid, but are working with a disability determination from the SSA.
- Do you have a Home and Community Based Services (HCBS) Waiver for Home Health Care? If you qualify for Medicaid and have a HCBS waiver, Medicaid will pay for in home health care-sometimes up to 24 hours per day of in home health care in order to keep people with disabilities more independent and at home.

Medicaid resources:

**Health Insurance Resources: A Guide for People with Chronic Disease and Disability**, 2<sup>nd</sup> Edition, by Dorothy E. Northrop, MSW, ACSW: Information at <http://www.nationalmssociety.org/multimedia-library/books/health-insurance-resources/index.aspx>

Medicaid State by State Descriptions and Plans  
<http://www.colorado2.com/medicaid/states.html>

Kaiser Family Foundation: Medicaid Benefits

2400 Sand Hill Road

Menlo Park, CA 94025

phone: 1-650-854-9400

fax: 1-650-854-4800

[http://www.kff.org/medicaid/benefits/state\\_main.jsp](http://www.kff.org/medicaid/benefits/state_main.jsp)

## Appeals

Any time a claim is denied through your health insurance company, you should consider appealing the denial. Appeals work for any type of insurance and can work for any type of expense including doctor's visits, hospital stays, durable medical equipment, and medication. But check your policy first, as there is no point in appealing a denial for a service or item that is not covered by your policy. Please consider the questions below when thinking about appealing a claim:

- Has a claim for coverage of a medication or piece of durable medical equipment been denied?
- Has your premium been increased dramatically?
- Has your medication changed tiers or gone from a flat co-pay to a percentage of the full cost of the medication?
- Has a doctor visit or stay in the hospital been denied?
- Is a doctor's bill more than you expected it to be?

Appeals resources:

National MS Society Web page on appealing a coverage denial or limitation by your health plan:

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

National MS Society Web page on health insurance appeal letters:

<http://www.nationalmssociety.org/download.aspx?id=517>

**Medicare Part D Appeals Manual** from the Medicare Rights Center:

<http://www.medicarights.org/appealsmanual.html>

Medicare Appeals information from Medicare.gov:

<http://www.medicare.gov/basics/appeals.asp>

**Health Insurance Resources: A Guide for People with Chronic Disease or Disability**, 2<sup>nd</sup> Edition, (Chapter 8): Information at

<http://www.nationalmssociety.org/multimedia-library/books/health-insurance-resources/index.aspx>

## **Life insurance**

If you are looking for life insurance options, consider the following question and resource in your search for life insurance information.

- Can you get life insurance through an employer or your spouse's employer?

Life Insurance resource:

National MS Society Web page on shopping for life, disability and long-term care insurance:

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

## **Long-term care insurance**

If you are in the market for long-term care insurance, please note that relatively few Long Term Care Insurers will sell to people with MS. Those that do may not advertise widely and may accept people on a case by case basis.

Long-term care resource:

**The Questions You Have, The Answers You Need** by Rosalind C. Kalb, PhD:

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

## **Short-term disability (STD) and Long-term disability (LTD) insurance**

If you currently are in the market for short-term or long-term disability insurance, consider the following questions:

- Do you have STD or LTD benefits through your employer?
- Have you disclosed your MS to your employer?
- Have you asked for accommodations at work?
- Are you actively using accommodations and are they assisting with your daily work?
- Have you had an evaluation with the department of vocational rehabilitation? If so, what was the outcome of the evaluation?
- Have you utilized your Family Medical Leave Act (FMLA) benefits?
- Has your doctor told you that you need to decrease your hours at work or stop working?

STD and LTD resources:

National MS Society Web page on STD/LTD:

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

National MS Society Web page on Employment and MS:  
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/employment/index.aspx>

JOIN THE MOVEMENT

1 800 344 4867 ■ [www.nationalMSSociety.org](http://www.nationalMSSociety.org)



National Multiple Sclerosis Society

Self Advocacy Worksheet (Sample – Health Insurance)

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 for your unique situation.

My co-pay for my MS therapy increased from \$40 per month to \$270.

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

I want to a) find out if what my insurance company is doing is legal, without informing my employer that I have MS, and b) go back to getting my MS therapy for \$40 per month.

Issue: Create a summary statement.

I cannot afford to pay \$270 per month for my MS therapy.

Because: I cannot afford the increase in cost for my prescription drug therapy,

I need or I want: to dispute the increase with my insurance company.

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: I have health insurance that covers my MS therapy and my symptoms are minimal. I do not want to inform my employer that I have... Cons: If I dispute the increase in cost for my MS therapy, my employer may discover that I have MS.

MS.	
I am willing/able to advocate for myself.	I cannot afford to pay five times as much for my MS therapy.
	Because of my income, I probably do not qualify for prescription drug assistance.

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
What is my insurance coverage for this prescription drug?	My insurance company's toll-free number	My MS therapy is covered by insurance, but it has been moved from a Tier 2 to Tier 3 drug.
What are my options?	National MS Society: 1-800-344-486	I learned: 1) insurers can legally shift drugs on their formulary from one tier to another; 2) I can appeal for re-instatement of \$40 co-pay; 3) my employer need not learn I have MS if I file an insurance appeal. I could consider a new health insurance plan that covers this drug at a lower cost, if I am eligible, and it is accessible either via my employer or perhaps by my spouse.
Do I have any other options for coverage?	My spouse's employer — I will call if necessary.	Only a possibility if my appeal doesn't work.
How can my doctor help me with an appeal?	My neurologist — His phone # 1-917-789-2000	His written support for my continuing on this therapy, and explanation for why I should not be placed on an alternative therapy.

Where do I find specific appeal information about my health plan?	My health benefits manual	My health plan outlines an appeal process and describes to whom I should address my concern.
---	---------------------------	--

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

My Rights	My Responsibilities
To appeal any decision about my health insurance benefits without implicating or informing my employer	To find out when and where to send the appeal, and how and when to follow up.
To ask my doctor for help in the appeal process, especially so he can say that I shouldn't be switched to a less expensive MS drug.	Get a letter from my doctor to include in my appeal.

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.

My employer's human resources department

My health plan administrator

My doctor

6. Brainstorm possible solutions to address your concern.

See 3, and 5 above.

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.

I will file an appeal with my insurance provider, comply with their appeals procedures and request that my doctor contact my insurance company, documenting my need for this specific MS therapy.

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>
My health plan could deny my appeal	Evaluate and consider eligibility for other health plans	

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

As above, if my appeal is not successful, I will evaluate and consider my eligibility for other health plans.

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.



National  
Multiple Sclerosis  
Society

## Self Advocacy Worksheet (Sample – Medicare)

### 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 for your unique situation.

I just received my Medicare card, though I am also still covered by my husband's insurance. We thought I should remain covered by his employer's insurance plan, but that contains a \$5,000 yearly limit on prescription drugs. My doctor wants me to start on an expensive MS therapy.

Do I need a Medicare prescription drug plan too? What about Medicare supplemental insurance? What is Medigap? Should I drop my husband's employer coverage? What happens when he retires?

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

I need information and advice about Medicare and insurance benefits so I have coverage for all of my medical needs — at the least cost to me.

Issue: Create a summary statement.

I am disabled and on Medicare, but need help from someone who can advise me about these and other benefits so I can make the best decisions.

Because: I have a variety of options for health care coverage,

I need or I want: to speak with somebody about insurance benefits and MS.

### 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
I have Medicare AND other health coverage.	My husband's human resources department doesn't understand my Medicare benefits or my husband's policy well enough to offer me good advice.
We can afford to pay for both.	I'm totally confused.

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

Question	Reference, Resource or Contact Information	Outcome
I need assistance understanding Medicare.	National MS Society:1-800-344-4867	Gained an understanding of Medicare supplemental coverage and costs, and Medicare drug coverage and costs. Will receive by mail information to review regarding my insurance options. Identified questions to ask insurance provider to determine next steps after my husband retires.
Are there other organizations that can assist with Medicare questions?	Medicare Rights Center:- <a href="http://www.medicarerights.org">www.medicarerights.org</a>	Another good source for information regarding Medicare benefits.
How do I find a good Medicare Part D plan?	Medicare Plan Finder: <a href="http://www.medicare.gov">www.medicare.gov</a>	This site will help me assess which Medicare drug benefit plan is best for me.

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

I learned the difference between Medicare, Medicare supplemental insurance and Medicare prescription drug insurance. I also learned what is and what is not covered for my health care needs. I learned where to get information about specific Medicare supplemental plans and Medicare drug plans and found out that if I want to enroll in either (or both) of them, I have to do so pretty soon, while I am new to Medicare, because there are deadlines.

My Rights	My Responsibilities
To find clear, accurate and useful information	Make an informed decision about enrolling in a Medicare Part D plan and a Medigap plan.
To stay in current insurance AND Medicare Part A, B & D and a Medigap plan.	To figure out how much insurance coverage (in addition to Medicare) I can afford. To research the best Medicare Drug and Medigap plan for my needs and enroll before the deadlines.
To stay in current employer health plan after my husband retires	To find out whether my husband and I will still be eligible for employer coverage after he retires, and how much it might cost us.

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 number 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>

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.



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

- 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.