



National
Multiple Sclerosis
Society

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.