



National
Multiple Sclerosis
Society

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.