



National  
Multiple Sclerosis  
Society

## Self Advocacy Worksheet (Sample – Family)

### 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.

My family used to be extremely close but since my diagnosis with MS everything has changed for the worse. My kids barely speak to me and avoid being around our home and my spouse and I constantly argue. I want my family to be as close as we once were and not allow MS to change the quality and quantity of time we spend as a family as well as how we communicate with each other. I hope to find a way to open communication and repair our family relationships.

Cause: Describe the cause for your unique situation.

Due to chronic fatigue and additional MS-specific symptoms such as drop foot and vision problems, driving is difficult for me at this time. This has placed additional strain on my spouse whom now is responsible for picking up and dropping off the children from school and recreational activities. Recently I also have missed several of my children's plays and games due to doctor appointments.

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

I aim to change the way I communicate with my family. I hope to offer more support to my spouse in other ways to alleviate her strain and change the way I interact with my children to help them learn about MS and not allow it to affect the way they see and communicate with me.

Issue: Create a summary statement.

Symptoms of my MS have put a strain on relationships within my family, especially regarding communication. I will use communication

and solution-seeking, not accusations, to create an open dialogue among me, my spouse and our children, and reunite our family.

Because: I love my spouse and children

I need or I want: to change the way we communicate with each other.

**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
Creating an open dialogue with my spouse will help address current problems and help us identify solutions. It may also strengthen our relationship.	We may just continue to argue, which could intensify and lead to a divorce.
Helping my children understand MS will encourage them to spend time with me and ask questions instead of continuing to avoid both MS and me.	The children may not want to learn about MS and may become even more afraid of both me and the disease after learning more about it.

- 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 do I open communication with my spouse instead of just arguing?	National MS Society (Relationship Matters) <a href="http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/relationship-matters/index.aspx">http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/relationship-matters/index.aspx</a> or call 1-800-344-4867	My spouse and I begin to communicate and develop a plan to strengthen our marriage.
How do I explain MS to my children?	National MS Society (list of resources for children: books, tapes, DVDs) <a href="http://www.nationalmssociety.org/multimedia-library/brochures/for-children--teenagers/index.aspx">http://www.nationalmssociety.org/multimedia-library/brochures/for-children--teenagers/index.aspx</a> or call 1-800-344-4867 to find your chapter and list of resources.	My children become less afraid of MS and are willing to spend time with me. I can answer the questions they

	<b>Keep S'myelin</b> (MS newsletter for kids) Call your chapter at 1-800-344-4867 or e-mail <a href="mailto:keepsmyelin@nmss.org">keepsmyelin@nmss.org</a> .	have or find resources to help explain.
Are there any MS support groups in my area for me, couples and/or parents with MS?	National MS Society (find your chapter) <a href="http://www.nationalmssociety.org/find-a-chapter/index.aspx">http://www.nationalmssociety.org/find-a-chapter/index.aspx</a> or call 1-800-344-4867 to contact your chapter and obtain a list of local support/self-help groups	We find the right support group for us.
Is there a way to obtain referrals for professional help, e.g. family counselors?	National MS Society (find your chapter) <a href="http://www.nationalmssociety.org/find-a-chapter/index.aspx">http://www.nationalmssociety.org/find-a-chapter/index.aspx</a> or call 1-800-344-4867 to contact your chapter and obtain referrals for counselors in your area.	We find the right counselor for our family or as individuals in order to work on our communication and family concerns.

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

My Rights	My Responsibilities
To communicate openly and effectively with my family.	To communicate with my family and offer them support as well.
To live in a peaceful environment.	To stop arguing with my spouse.
To remain living with my family.	To ensure that my family can continue living with me.
To seek professional help when a problem is too big to handle on my own.	To acknowledge my family members' stake in resolving our problems and let them be part of crafting solutions.

5. Identify who has authority in 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 have the most authority regarding my own personal situation. My marriage is a partnership; therefore my spouse and I have equal authority over our marriage and children.

6. Brainstorm possible solutions to address your concern.
  - A) Hold a family meeting to discuss issues and set up a plan.
  - B) Host individual time with my spouse and each child to create an open dialogue.
  - C) Attend a National MS Society support group that meets my needs (for people with MS, couples, or parents with MS).
  - D) Attend personal and or professional counseling.
  
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 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>
How can we trust a stranger to help us with private family matters?	<p>We can obtain referrals from the National MS Society for counselors who are familiar with MS and family dynamics.</p> <p>We can also attend a self help group to meet people dealing with similar issues, as well as to help us become more comfortable communicating with each other.</p>	Find your chapter and obtain referrals to counselors and self help groups by calling the National MS Society at 1-800-344-4867.
We are all too busy and there is too much work around the house to make time for a family meeting. How can you even suggest counseling or a support group?	Our family is too important to not make time. We can find resources, e.g. hire a housekeeper or enroll the kids in a carpool for afterschool activities, to make time to talk. We can try a support group or family counselor.	Find your chapter and obtain referrals to counselors and chore services by calling the National MS Society at 1-800-344-4867.

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

If communication does not improve around our home, I am willing to try family counseling with my wife and children.

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.

If family negotiations do not quickly yield better results, I may have to think about steps I can take on my own. Time apart may be helpful. As a last resort, I may have to consider options for more formal and lasting separation. At that point, consulting a divorce attorney would be advisable.

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.