



National
Multiple Sclerosis
Society

Community Accommodations Resources For Self Advocacy

Introduction

This guide offers informational resources to help people with multiple sclerosis engage in self advocacy to more fully and comfortably participate in their communities.

The National MS Society's Self Advocacy Worksheet complements this guide by helping you plan your course of action. This worksheet is available at <http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-in-the-community/download.aspx?id=8130>. Reference it to assess your circumstances, concerns or needs, and to identify your goals for self advocating within the community. You can also find a sample worksheet at <http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-in-the-community/download.aspx?id=8131>.

Community is defined broadly to encompass transportation, places of business, and public facilities including parks and walkways. Community self advocacy is often geared toward requesting:

- **A modification to a building or facility**, such as installation of a power-assist door or a curb cut for better accessibility.
- **An amendment to policies or practices** to create a more accommodating or welcoming environment for people with disabilities.
- **An apology** for an inappropriate past action or statement.

The first step: Ask for good customer service

For most community access concerns, the quickest and easiest way to reach resolution is to approach the facility's management. Explain your objective, request good customer service, and attempt to partner with the management to achieve a mutually agreeable solution. Whether you are speaking as a taxpayer to your town's mayor or as a customer to the local pizzeria owner, there is nothing stopping you from asking for whatever you need for better access.

- Be kind.
- Be clear. What do you need? Explain why.
- Be creative. If your first choice solution is a non-starter, what else would improve the situation?
- Be persistent. What else can be done? How and when can you follow up?

Even when there is a clear violation of accessibility standards, your best first course of action is to politely ask for the necessary change.

Gather the facts & consider your course of action

- Reference the National MS Society's accessibility site checklist. (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-in-the-community/download.aspx?id=9510>) It will help you determine whether a particular facility meets accessibility standards and identify problematic areas.
- Analyze your strengths regarding your situation, including:
 - Your business. Are you prepared to stop doing business with this establishment if it does not accommodate you? Do you have other viable options?
 - Your expertise. Can you create broader awareness regarding the needs of people with disabilities or explain proper etiquette? Can you suggest some easy-to-implement, low-cost solutions?
 - The entity's belief in themselves as good corporate citizens or as a responsive governmental body. Can you appeal to their sense of what is right?
 - Force in numbers. Are there others experiencing the same or similar challenges? Can you demonstrate that your issue is not unique to you and that others are affected too?
 - People of influence. Do you have relationships with others who might expeditiously aid you in resolving your situation?
 - Influence from professional organizations. Is the facility in question a member of any professional organization, such as the Better Business Bureau? Does the organization adhere to a code of ethics or offer a means of arbitrating disputes?*
 - Public opinion and media outlets. Is your story appealing to the media? Would the public likely be sympathetic to it?*
 - Vulnerability to complaint under the ADA or suit under your state's Human Rights Law. What laws apply to your situation? How long is it likely to take to get resolution using the legal system?*

If your initial request for customer service isn't successful, these sources may aid you in achieving your desired outcome.

*NOTE: Discussing any of the last three sources of strength may be perceived as aggressive. Exhaust all amicable options first.

Reflect on what constitutes a victory for you. Are you pursuing the issue for your own access or on behalf of others in the community? If you win a lawsuit that requires a modification, but now feel uncomfortable at that venue, have you met your objective?

Know your rights: The Americans with Disabilities Act (ADA)

The 1990 Americans with Disabilities Act (ADA) created new federal protections against discrimination for people with disabilities, allowing millions of Americans to more fully participate in all facets of their communities. The ADA applies to nearly everyone with multiple sclerosis and includes two sections which apply directly to community accommodations: Title II deals with transportation, and Title III protects the rights of people with disabilities regarding public accommodations.

Following are some online resources about the ADA.

❑ **How does the ADA specifically serve people with MS?**

<http://www.nationalmssociety.org/download.aspx?id=66>

Or, to request a printed version of this pamphlet by mail, call an MS Navigator® at 1-800-344-4867.

❑ **What are the ADA requirements for buildings and facilities?**

<http://www.access-board.gov/adaag/html/adaag.htm>

❑ **How does Title II of the ADA address transportation issues?**

<http://www.nationalrehab.org/website/history/ADATitleII.pdf>

❑ **How does Title III of the ADA address public accommodations?**

<http://www.sanantonio.gov/ada/EtHandbook6.asp?res=1024&ver=true>

<http://www.nationalrehab.org/website/history/ADATitle%20III.pdf>

❑ **Where can I find ADA technical assistance?**

The National Network of ADA Centers offers links to 10 regional offices with professional staff able to provide ADA compliance training and technical support to individuals and businesses.

<http://www.adata.org>

❑ **Where can I find additional ADA resources?**

ADA Regulations and Technical Assistance Materials:

<http://www.ada.gov/publicat.htm#Anchor-14210>

❑ **What is the process for appeals under the ADA?**

This New York State brochure explains how to file appeals or complaints related to ADA Titles I, II and III.

<http://www.cqcapd.state.ny.us/DisabilityRightsADA/ADA.htm>

❑ **Are there resources specific to accessibility for restaurants?**

http://www.restaurant.org/legal/law_ada.cfm#overview

Guidelines for Restaurants and Accessibility:

<http://www.cga.ct.gov/2006/rpt/2006-R-0335.htm>

□ **Where can I read in greater detail about the ADA and civil rights for people with disabilities?**

ADA/Disability Rights

Pocket Guide to the ADA: Americans with Disabilities Act Accessibility Guidelines for Buildings and Facilities. Evan Terry Associates, Editor, \$30, John Wiley & Sons, Inc., ISBN-13: 9780470108703

Understanding Disability: Inclusion, Access, Diversity and Civil Rights by Paul T. Jaeger & Cynthia Ann Bowman, \$52, Praeger Publishers (2005) ISBN #0275982262

As important as the ADA has been in establishing standards of accessibility, it has limits:

- The ADA does not apply to all settings. For example, private clubs and religious organizations are exempt.
- Historic buildings are subject to different standards.
- Not all accommodations are considered “reasonable.” A business’s ability to pay for changes is taken into account.
- Filing an ADA complaint is extremely time-consuming. Formal complaints should be reserved for situations where amicable negotiation has failed.

Consider attempting a range of other self advocacy techniques before filing an ADA complaint. Some states have civil rights laws which may also protect your right to access public accommodations. Some states have accessibility standards that are even more rigorous than the federal standards.

Additional resources

Following are some links to help you identify the facts and possible solutions for your particular situation. Resources not developed by the National MS Society are listed for the value they may provide, but the Society cannot assume responsibility for their content or associated links.

Accessibility

There is a wealth of information available regarding making spaces more accessible and safer for people with disabilities. Accessibility modifications can range from relatively quick and inexpensive (installing a grab bar) to costly (major architectural changes or installing lifts).

□ **Are there guidelines for accessibility in the home?**

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/mobility-and-accessibility/environmental-adaptations/download.aspx?id=312>

Or, to request a printed version of this pamphlet by mail, call an MS Navigator® at 1-800-344-4867.

□ **Must accessibility in the home be expensive?**

<http://www.nationalmssociety.org/download.aspx?id=277>

Or, to request a printed version of this pamphlet by mail, call an MS Navigator® at 1-800-344-4867.

□ **Are there resources regarding accessibility for churches?**

That All May Worship: An Interfaith Welcome to People With Disabilities, National Organization on Disability, www.nod.org (2005). Contains information for religious congregations on welcoming people with disabilities and chronic illnesses, as well as providing a supportive environment for caregivers.

Disability etiquette and sensitivity toward others

Sometimes a community self advocacy issue is, at its core, about a lack of awareness or sensitivity to disability etiquette by an employee or business owner. In the event of an offense, you might:

- Seek an apology from the management of the organization.
- Request a refund of any inappropriate fees that were charged.
- Recommend staff training to avoid similar situations in the future.
- Request that disciplinary action be considered for the involved staff (reserved for egregious situations).

□ **What resources are available to train employees and the public about appropriate language and behavior?**

- Detailed disability awareness and etiquette resource produced by the City of Sacramento, Calif.
http://www.cityofsacramento.org/adaweb/learning_about_disabilities.htm
- Easter Seals Disability Etiquette
http://www.easterseals.com/site/PageServer?pagename=ntl_etiquette
- Community Resources for Independence has several articles on disability etiquette at <http://www.crinet.org/etiquette.php>.

Transportation

The ADA requires that no individual be denied access or the benefit of transportation services due to a disability. Title II of the ADA has provisions for fixed route transportation systems, such as bus lines, and for demand-response services, such as taxi cabs.

Transportation providers are often large entities, with many employees, routes, and vehicles spread throughout a region at any given time. If you experience a problem with transportation service, effective self advocacy begins by providing

feedback to the transportation provider's central office. Some providers have comment lines or a staff person dedicated to ADA compliance.

Common transportation self advocacy concerns include:

- Late arrival, or no arrival at all
- Discourteous driver
- Lack of appropriate equipment or facilities to accommodate a person's disability

In all of these cases, the provider's management is unlikely to be aware of the problem if you do not bring it to their attention. Keeping the management informed of ongoing problems is your best avenue to work toward needed changes.

Some Web sites with information specific to various types of transit are:

Specifications regarding transportation facilities and the ADA

- Airports: <http://www.access-board.gov/adaag/checklist/TransportationAirports.html>
- Bus Stops: <http://www.access-board.gov/adaag/checklist/TransportationBus.html>
- Terminals & Stations: <http://www.access-board.gov/adaag/checklist/TransportationFixed.html>

Air travel

- Federal Aviation Administration
http://www.faa.gov/passengers/passengers_disabilities/
- The U.S. Department of Transportation's Aviation Consumer Protection Division
<http://airconsumer.ost.dot.gov/publications/flyrights.htm#pass>
- The Federal Transit Administration
http://www.fta.dot.gov/civil_rights.html

Other public transit

- Project Action: Easter Seals' program advocating for accessible community transportation
http://projectaction.easterseals.com/site/PageServer?pagename=ESPA_homepage



National Multiple Sclerosis Society

Self Advocacy Worksheet (Sample – Community Accommodations)

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.

I would like access to Smith Hall to join my family and friends for a Friday night fish fry.

Cause: Describe the cause of your unique situation.

I use a power wheelchair because multiple sclerosis has impaired my ability to walk. It is impossible for me to climb the stairs at Smith Hall.

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

In order to dine at Smith Hall, I would like a ramp installed for access to it, or access via another door.

Issue: Create a summary statement.

I would like access to Smith Hall to join my family and friends for a Friday night fish fry. Because multiple sclerosis has impaired my ability to walk, I use a power wheelchair and cannot climb the stairs to the restaurant.

Because I use a power wheelchair, I need or I want a ramp or another means of access to join my family and friends at Smith Hall.

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
The food at Smith Hall is excellent.	I cannot access the restaurant any longer.
If I approach management, I may gain	I may be perceived as a difficult customer.

access to the restaurant.	

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
Am I protected by the ADA?	Department of Commerce 1-608-266-8731	To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered. <i>http://www.ada.gov/cguide.htm</i>
What are the requirements for business compliance with the ADA?	ADA Wisconsin Partnership 1-608-246-3444 or ada@eri.wi.org	Any facility opening for first occupancy after Jan. 26, 1993, must meet a fairly strict accessibility standard — being "readily accessible" to people with disabilities. That standard applies to everything from parking spaces to entranceways to restrooms. • Facilities that opened prior to the 1993 cutoff are not required to provide full accessibility. However, any major renovations that take place after Jan. 26,

		<p>1992 must make the altered areas readily accessible to individuals with disabilities, to the extent feasible.</p> <ul style="list-style-type: none"> • The ADA also requires facilities that opened prior to the 1993 cutoff to remove architectural and communication barriers when such changes are "readily achievable." Readily achievable changes are those that are easy to carry out without much difficulty or expense. <p><i>http://www.restaurant.org/legal/law_ada.cfm#overview</i></p>
<p>What are the requirements for business compliance with the ADA? (cont.)</p>	<p>ADA Accessibility Guideline for Buildings http://www.access-board.gov/adaag/html/adaag.htm#rest or 1-800-872-2253 (v)</p>	<p>ADA Title III: Public Accommodations</p> <p>Title III covers businesses and nonprofit service providers that are public accommodations; privately operated entities offering certain types of courses and examinations; privately operated transportation; and commercial facilities. Public accommodations are private entities who own, lease, lease to, or operate facilities such as restaurants, retail stores, hotels, movie theaters, private schools, convention centers, doctors' offices, homeless shelters, transportation depots, zoos, funeral homes, day care centers, and recreation facilities including sports stadiums and fitness clubs.</p> <p>Public accommodations must comply with basic</p>

		<p>nondiscrimination requirements that prohibit exclusion, segregation and unequal treatment. They also must comply with specific requirements related to architectural standards for new and altered buildings; reasonable modifications to policies, practices, and procedures; effective communication with people with hearing, vision, or speech disabilities; and other access requirements. Additionally, public accommodations must remove barriers in existing buildings where it is easy to do so without much difficulty or expense, given the public accommodation's resources.</p>
<p>What if a restaurant fails to comply with the ADA?</p>	<p>Disability Rights Wisconsin 1-608-267-0214 http://www.disabilityrightswi.org/priority-issues/barriers-to-accessibility/</p>	<p>Complaints of Title III violations may be filed with the Department of Justice. In certain situations, cases may be referred to a mediation program sponsored by the Department. The Department is authorized to bring a lawsuit where there is a pattern or practice of discrimination in violation of Title III, or where an act of discrimination raises an issue of general public importance. Title III may also be enforced through private lawsuits. It is not necessary to file a complaint with the Department of Justice (or any Federal agency), or to receive a "right-to-sue" letter, before going to court. For more information, contact:</p> <p>U.S. Department of Justice Civil Rights Division</p>

		<p>950 Pennsylvania Avenue, NW Disability Rights Section - NYAV Washington, DC 20530 www.ada.gov 1-800-514-0301 (voice) 1-800-514-0383 (TTY)</p> <p><i>http://www.cqcapd.state.ny.us/DisabilityRightsADA/ADA.htm</i></p>
Other sites	<p>U.S. Department of Justice Civil Rights Division www.ada.gov 1-800-514-0301 (voice)</p>	
	<p>ADA Accessibility Guideline for Buildings http://www.access-board.gov/adaag/html/adaag.htm#rest or 1-800-872-2253 (v)</p>	

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

My Rights	My Responsibilities
I am protected by the ADA due to my disability.	Complaints of Title III violations may be filed with the Department of Justice. In certain situations, cases may be referred to a mediation program sponsored by the Department.
Public accommodations, including restaurants that have opened after Jan. 26, 1993, must comply with basic nondiscrimination requirements. This includes prohibiting exclusion, segregation, and unequal treatment for people with disabilities.	The Department is authorized to bring a lawsuit where there is a pattern or practice of discrimination in violation of Title III, or where an act of discrimination raises an issue of general public importance. Title III may also be enforced through private lawsuits. It is not necessary to file a complaint with the Department of Justice (or any Federal agency), or to receive a "right-to-sue" letter, before going to court. For more information,

	<p>contact:</p> <p>U.S. Department of Justice Civil Rights Division 950 Pennsylvania Avenue, NW Disability Rights Section - NYAV Washington, DC 20530 www.ada.gov 1-800-514-0301 (voice) 1-800-514-0383 (TTY)</p>
<p>Properties on or eligible for listing on the National Register of Historic Places, or properties designated as historic under state or local law, are subject to less stringent requirements if full compliance with ADA would threaten their historical significance.</p>	
<p>Smith Hall is a historic 1883 landmark and may be subject to less stringent requirements.</p>	

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.

Smith Hall

General Manager: Name
Manager: Name

Phone: 1-555-555-5555
Address: North Street

6. Brainstorm possible solutions to address your concern.
 - Install ramp or lift at front stair entrance.
 - Offer other means of entrance toward rear of restaurant, using lift for ramp.
 - My preferred solution is to gain access to the restaurant, whether via the front or a side door.
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.
 - Restaurants built after January 1992 must comply with the ADA.
 - Because construction of Smith Hall predates the ADA, it is required to meet less stringent requirements.

- *My preferred solution is to gain access to the restaurant, whether via the front or a side door.
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>
Smith Hall Restaurant is designated as historic and is exempt from ADA accessibility standards	It is true that properties on or eligible for listing on the National Register of Historic Places, or properties designated as historic under state or local law, are subject to less stringent requirements if full compliance with ADA would threaten their historical significance.	
	This request, though, is really a request for better customer service.	
	I would very much like to continue the tradition of enjoying your Friday night fish fry.	

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 would settle for access from the back door, not the front door.

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.

Complaints of Title III violations may be filed with the Department of Justice. In certain situations, cases may be referred to a mediation program sponsored by the Department. The Department is authorized to bring a lawsuit where there is a pattern or practice of discrimination in violation of Title III, or where an act of discrimination raises an issue of general public importance. Title III may also be enforced through private lawsuits. It is not necessary to file a complaint with the

Department of Justice (or any Federal agency), or to receive a "right-to-sue" letter, before going to court. For more information, contact:

U.S. Department of Justice
Civil Rights Division
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www.ada.gov
1-800-514-0301 (voice)
1-800-514-0383 (TTY)

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

The food at Smith Hall is excellent and the atmosphere is festive.
We have enjoyed eating there for years.
I'd like to keep the tradition alive by continuing to eat there.

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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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. Three empty rows for notes.

- 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

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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.