



Advocacy Handbook

Tips for Citizen Involvement in Public Policy

Our Mission Statement

To eliminate Alzheimer's disease through the advancement of research and to enhance care and support for individuals, their families and caregivers.

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Introduction

The Alzheimer's Association is dedicated to improving the lives of those afflicted with Alzheimer's disease and their families and, through research, finding treatment and cure. One of the most effective tools we have is public policy advocacy. This means we work to change laws, regulations, and public programs to accomplish our two-fold mission.

Our work in public policy moves our concern for persons with Alzheimer's disease and their families out of our homes and into the capitals of every state, and into the offices of virtually every U.S. Senator and Representative, even into the White House. The payoff has been phenomenal to date: substantial increases in federal research funds, growth in state supported services, and recently, commitment to Family Caregiver Support.

This handbook is designed to make public policy advocacy more accessible to you so you can be a part of our successful efforts. In the pages that follow, you will find easy-to-use tips on such things as calling, visiting or writing a public official, how to reach your state capitol; even a glossary of legislative terms.

You'll see that most of the ideas in this handbook are simple, common sense suggestions. **Advocacy is not complicated or technical.** The most important ingredient is you - your personal experiences, your commitment to help make a difference, and your willingness to communicate with your elected representatives.

The payoff is tremendous, both for what you can achieve and for the gratification you receive for making a difference in the lives of those affected by this devastating disease. Welcome to the Alzheimer's Association Public Policy advocacy program!

WORKING TOGETHER FOR CHANGE

WHY?

- Because elected officials and government agencies don't know what families need unless we tell them.
- To assure adequate, appropriate, and affordable services for persons with Alzheimer's disease and their caregivers.
- To increase funding to find the cause and treatment of Alzheimer's.
- To establish a fair system of financing long term care.

...AND OUR ADVOCACY WORKS!

The Association's growing advocacy efforts have already achieved breakthroughs by:

- Increasing federal funds for research to over \$500 million annually.
- Shaping dozens of bills, regulatory actions and program designs in states across the nation.
- Securing federal funding to support state programs for Alzheimer services.
- Raising the awareness of policy makers and the general public about the real health care crisis -- long term care and family caregiver burden.

OUR POLITICAL SYSTEM NEEDS CITIZEN PARTICIPATION TO WORK!

The strength of our advocacy effort is rooted in the thousands of family members who can be active in public policy activities.

The key to a Chapter's effectiveness is its vital network of volunteer advocates. Your local Alzheimer's Association Chapter has a standing public policy committee and many opportunities to be an active volunteer in public policy. Get involved!

VOLUNTEERING WITH THE ALZHEIMER'S ASSOCIATION

- **Join the Chapter Public Policy Committee!**
- **Speakers Bureau:** Volunteer to help motivate and educate others about public policy.
- **Fact Gathering:** Do phone, library and legwork to assist the public policy committee in developing positions or legislation.
- **Issue Coordinating:** Under the direction of the Chair or committee, research and analyze possible strategies and tactics to move a particular legislative proposal or issue.
- **Writing:** Write articles on public policy for your Chapter newsletter.
- **Phone banking:** Volunteer to call support group leaders and Chapter members to remind them to participate in upcoming events or respond to issues.
- **Attending state and federal** advocacy days and forums.
- **Participating in a Coalition:** Represent the Chapter in a coalition, a diverse group of organizations working together on an issue.
- **Agree to testify** at hearings and forums.
- **Create your own job:** Is there an Alzheimer's issue really burning you up...that you think needs action? Make a suggestion to the public policy chair about what you want to do or can do best.

WRITING TO A PUBLIC OFFICIAL

WHY?

State and federal legislators pay close attention to their mail. Letters are one important way for them to know whether an issue matters to the people they represent. The volume of letters a public official receives on an issue can affect the way he/she votes. One letter can make the difference!

TIPS

- Write a personal letter. It is much more effective than a form letter. Tell your own story about how the issue affects you, your family or your community. (See model letter on page 7)
- Identify yourself as a constituent and/or a member of the Alzheimer's Association.
- Identify the bill number or issue on which you want action in the first paragraph of your letter, and state what action you want.
- Try to say it in one page (two pages at most) and be sure your return address is legible.
- Ask a question in your letter. By doing so, you show that you expect to continue the dialogue with the elected official.
- Be polite and persuasive (No name calling or threats).
- Send a copy of your letter to your Chapter office so they can track the legislator's responsiveness.

• To write to a Member of Congress:

The Honorable _____ The Honorable _____
United States Senate US House of Representatives
Washington, DC 20510 Washington, DC 20515

Dear Senator Doe,

Dear Congressman (woman) Doe,

• To write to a Governor or state legislator:

The Honorable
State House, Room ____
Your State Capitol, Zip

Dear Representative/Senator/Governor Doe,

Model Letter

Date

The Honorable _____
Any State Senate
State House, USA 99999

Dear Senator Doe:

I'm writing to you about Assembly Bill 770. I'm 68 years old, retired for 4 years now, and have lived here in your district since just after the Korean War. I'm writing to you late at night, because my husband Frank has finally settled down and I have a minute to myself. I've never written a letter like this before.

Frank has Alzheimer's disease. Alzheimer's is a progressive disease of the brain that eventually will kill my husband. There are times when I think it will kill me, too. There is no one other than me that can take care of Frank; all our children and relatives are far away, and sometimes they don't really understand what it's like to be with him all day, every day, watching his confusion and his frustration with the loss of so many of his abilities and activities. The support group at the Alzheimer's Association gave me a book about caregiving called "The 36 Hour Day," which I think summarizes what my life has been like for most of the last 4 years.

I would like you to support AB 770 because it would establish a respite program for caregivers like myself. For a small investment of funds, this kind of program would give me (and hundreds like me) a break from time to time, so I can keep going. I want to keep providing the care Frank needs, but sometimes it is overwhelming. Right now, I can't even get away to see the doctor about some of my own problems. This bill would provide temporary care for Frank, either in our home, or in a day care center or other facility, so I can take care of myself.

Would you please let me know what you will do? Thanks.

Sincerely,

Betty Middleton
Anywhere, USA

ALERTS

WHAT? *ALERTS! are printed or phoned communiques designed to bring our grassroots advocacy network to life.*

WHY? *The Association uses ALERTS! to generate constituent phone calls, letters and e-mails to a state or federal elected official when he or she is about to make a decision on one of our key policy issues. (Sometimes ALERTS! are used to call people out for hearings, town meetings, and rallies.)*

- TIPS**
- Act immediately. ALERTS! require a quick and timely response.
 - Messages based on ALERTS! can be sent by letter, phone, or telegram.
 - Say exactly what you want. (e.g. Support the Family Caregiver Support Bill, House Bill #423) Ask for a commitment.
 - Be personal. Explain what the bill or proposal will mean to you and your family and others like you in your community.
 - Ask your family, friends, coworkers, and support group members to send a message, too.
 - Sign up for the National Alzheimer's Advocacy Network in order to receive ALERTS! on federal issues. (See page 19.)

VISITING A PUBLIC OFFICIAL

WHY?

Person to person visits are the most effective way of letting a public official know about you, your issues, and the Association.

TIPS

- Do your homework on the issues, and if possible, on the person with whom you will meet (such as the person's committee assignments and interest in your issues). Know ahead of time what you want to say and stick to the point.
- Lead with your own story. Let the official know what Alzheimer's means to you, your family and your community.
- Go with a group, with a plan for a spokesperson and an order of speaking. Practice through a role play first.
- If you meet with an aide and not a legislator, don't panic. Legislative aides are the eyes and ears of their bosses. They will communicate your message.
- Visit state and federal legislators in their district, when possible. They are often more relaxed and receptive when they are away from the capitol.
- Avoid jargon and insider acronyms.
- Keep it simple, direct, upbeat, and brief!
- Have a condensed version of your key points (2 minutes) ready for a wrap-up or in case your meeting time gets cut.
- Policy makers expect to be asked for assistance. Make a specific request for support.
- Bring a fact sheet (to leave behind) outlining your basic message, with details on how to reach you. Include information about your Chapter and its services.
- Write a thank you note, sending requested information, or otherwise following up on any interest or commitments expressed by the official in your meeting.

CALLING AN ELECTED OFFICIAL

WHY?

Elected officials and other government decision-makers pay attention when citizens take the time to call and express their views on an issue. It may be quicker and easier than writing. If an issue is moving fast, it may be the only way to get your message through in time to make an impact.

TIPS

- Prepare your remarks before you call.
- Don't be surprised if you don't speak to the official directly. Staff who answer or respond to the majority of constituent calls have the official's "ear" and will see that your comments are recorded and passed on.
- Identify yourself as a constituent.
- Say exactly what you are calling about (bill number, issue, etc.).
- Say what you want the official to do, such as vote against a budget cut, or sign a respite bill.
- Leave your name, address and phone number.
- Be positive and avoid debating at length.
- Calling local offices of federal or state officials is o.k., but calling their capitol office carries more punch. To call a member of the U.S. Senate or House, call (202) 224-3121 and ask for her/him by name. For a state official, call the central switchboard at your state capitol to be connected.

HOTLINES

- Call your governor and "weigh in" on an issue or a particular vote. (Your state capitol switchboard can tell you if an 800 number hotline exists.)
- Call the White House and register your opinion with the President by calling (202) 456-1111 any day between 9:00 a.m. and 5:00 p.m. Eastern Time.

PARTICIPATING IN A PUBLIC HEARING OR FORUM

WHY? *Hearings, town meetings, and forums can give us the chance to put your issues before policy makers and the general public and to show your support. They are also a way to learn more about how the policy making process works, and to monitor the work of public agencies and bodies.*

- TIPS**
- Arrive early to receive handouts and reports, and to adjust to changes in meeting room or schedule.
 - Wear Association colors (purple and white) or buttons, to draw attention to your presence. Your presence is a sign of public opinion!
 - Be sure to sign in so your presence is recorded.
 - Sit in front, where you can be seen.
 - Bring handouts or position papers for distribution.
 - If there is an opportunity for questions, ask one about Alzheimer's or long term care. (Think about it ahead of time so that you can be precise.)
 - Use the meeting as an opportunity to approach a hard to reach legislator or other official if you can do it without being rude.
 - Take photos for your Chapter newsletter.
 - At the end of the meeting (when they are less likely to be distracted by meeting details) introduce yourself to the staff that is handling the meeting.
 - **Bring along a friend.**
 - Write a follow up letter to officials who express an interest in or support for your issues.

TESTIFYING BEFORE A PUBLIC BODY

WHY?

Public officials want comments and suggestions about a particular bill or issue. In many situations, public hearings are required by law before a regulation or statute can be approved, amended, or implemented. While many of these take place in the capitol, many public bodies hold "field hearings".

***Before testifying, be sure to be in touch with your Alzheimer's Association Chapter!** It is important that the message we send to public officials be consistent and coordinated with other Association activities. Telling the "Alzheimer's story" together can have a major influence on policy decisions.*

TIPS

- Think of testifying as telling **your** story; an interesting beginning that draws people in, an exciting middle, and a clear conclusion. Anecdotes about your caregiving experiences are especially valuable.
- Develop an easily understood 5-10 minute statement, including your strongest facts, arguments for changes you would like to see made, and real examples of the ways people are affected by the matter under discussion. If you can, offer rebuttal of the opposition's main points.
- Practice your testimony.
- Prepare a two minute version of your statement in case you get cut short, as well as a complete written statement to submit for the record.
- If possible, go to another meeting of the committee or public body and observe how the testimony of others is received.
- For more detailed information about preparing testimony, see the Chapter Public Policy Manual. For assistance, contact the National Public Policy Division staff. (See "Resources," page 19.)

INFLUENCING THE MEDIA

WHY?

Visibility for issues influences public opinion and the actions of public officials. Making the case for a position on a bill or issue in any of the various media adds pressure upon public officials to act on issues. Above all, there are several ways that individual advocates can get their point of view into the media.

TIPS

- One way to get a point of view across is to write a letter to the editor of your local paper. These are often some of the most watched parts of local media by legislators and other elected officials.
- If you write a letter to the editor, be concise, be timely, and above all, don't assume that readers know jargon, buzz words, and the issues.
- Carefully follow the instructions for submitting letters to the editor described on the editorial page.
- Call in to a local radio talk show. If an issue like health care reform is being discussed, explain how Alzheimer's fits into that broader context.
- Make yourself available for speaking to the media about your family's situations related to Alzheimer's disease through your chapter public policy or public relations committees.
- Work with the chapter communications committee or staff to help build and maintain the chapter press list and do press calls to follow up on press releases on public policy issues.

COMMON ABBREVIATIONS

AAA	Area Agency on Aging
AARP	American Association of Retired Persons
ADL	Activity of Daily Living (activities performed for oneself in the course of daily living, such as dressing, bathing, and feeding).
AoA	Administration on Aging (federal agency responsible for funding many local services)
HCFA	Health Care Financing Administration (agency that oversees Medicare and Medicaid)
NARFE	National Association of Retired Federal Employees
NCCNHR	National Citizens' Coalition for Nursing Home Reform (advocates for quality of care in long term care facilities)
NIA	National Institute on Aging (federal agency; coordinates and funds Alzheimer and other aging related research; one of the 14 National Institutes of Health)
NIH	National Institutes of Health (federal agency; directs government funded research programs)
OBRA	Omnibus Budget Reconciliation Act (annual federal budget law)
OBRA '87	1987 Budget Act that contained the Nursing Home Reform Law regarding patients rights, restraints, etc.
OMB	Office of Management and the Budget (for the President)

GLOSSARY OF LEGISLATIVE TERMS

Act	Legislation that has been passed by a legislative body and signed into law by the executive.
Advocate	Literally, "one who is a voice on behalf of another"; public policy volunteer.
Aide	An assistant to a public official. (Also "staff", "staffer")
Amendment	The proposal by a member of a legislature to alter the wording of a bill under consideration.
Appropriation (Budget)	Legislation that directs the spending of public funds for a specific program agency or other purpose authorized by law.
Authorization	An act that creates or extends a program.
Bicameral	A legislature consisting of two houses.
Bill	A proposed law that is introduced to a legislative body.
Calendar	A listing of items for action by a committee or house of a legislative body; public document.
Caucus	An informal meeting of a group of members of a legislative body; sometimes convened based on interest or party affiliation (as in Elder Caucus).
Committee	A sub-group of a legislative body permanently established by rules to consider and report legislation and to monitor the implementation of programs enacted; organized by subject area, as in Health and Welfare Committee.
Conference Committee	A meeting between members of the House and Senate to iron out a compromise between different versions of a bill. Once a compromise is worked out, the conference report is voted upon and sent on to the Executive for approval.
Convene	To assemble, call together a meeting.
Ex Officio	The holding of one office by virtue of holding another; for example, the Lieutenant Governor of California is ex officio a member of the Board of Regents.
Fiscal Impact	The effect of a proposal upon a budget.
Floor	A colloquialism describing the interior meeting room of a legislative body; matters before the body are referred to as "on the floor" or "going to the floor"

Hearing	A committee meeting where testimony is taken from witnesses about an issue or specific bill.
Initiative	A proposal put directly before voters, bypassing the legislative process.
Joint Resolution	A measure offered in one house and agreed to by the other; such as those passed declaring Alzheimer's Awareness Month.
Journal	The official chronological record of proceedings. (Also "Digest", "Record")
Lobbyist	A person paid to represent the interests of a group to a governmental body.
Mark-up	The process by which a subcommittee or committee revises legislation. Once completed, the measure is ready for debate. (Also "Draft")
Officers	That portion of the legislature elected by its members to serve in positions of authority, such as Speaker of the House. (Also "Leadership")
Passage	Favorable action on a measure.
Quorum	The number of members required to be present before business can be transacted.
Reading	The presentation of a bill before either house by reading the title thereof; a stage in the enactment of a bill.
Referendum	The method by which a measure adopted by a legislature may be submitted to popular vote.
Rules	The methods of procedure adopted by a body for its own governance.
Session	The period during which a legislature meets, set by each state's constitution.
Skeleton Bill	In some states, a measure introduced in outline form, substance to be added at a later date.
Table	A motion to delay matters indefinitely. (Also "Postpone")
Unicameral	A legislature consisting of one house, such as in Nebraska or a city or county council.
Veto	The Executive's formal disapproval of legislation. A bill can become law if an override vote is successful in each house of the legislature. In Congress, this requires a two-thirds majority. In some states, Governors have authority to veto single line items of an appropriation (i.e., the line item veto).

Acknowledgements

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