



Fact Sheet

Advocacy Tips for Caregivers

A Call to Action

Families—not institutions—provide the majority of care to chronically ill and disabled persons. These families know the enormity of the burden in caring for someone with Alzheimer's or Parkinson's diseases, stroke, traumatic brain injury, or other long-term conditions. They also know the challenges in locating appropriate advice services, and respite.

Personal experiences with community agencies, round-the-clock care, and financial hardships mean families know what the important issues are. This puts family caregivers in a unique position to act as advocates. Caregivers can educate elected officials charged with development of public policy and funding priorities.

This fact sheet offers tips for effective strategies for families to get involved in local, state, or federal advocacy efforts.

How Families Can Help Effect Change at the Public Policy Level

Write or E-mail a Letter to Your Elected Representative:

Representatives rely on communication from their constituents to keep them informed and to know where

constituents stand on critical or controversial issues.

- A personal letter or e-mail is an effective method to get your message across.
- Write legibly, type, or e-mail your message and try to keep your communication to one brief page.
- Make your message to the point. Example: *"I'm writing in support of HR 1, the Long-Term Care Act."* (Refer to the bill name or number, if you can.)
- Give a reason for your position (support or opposition). A personal experience is often powerful in establishing your case.
- Let them know what you expect. Example: *"I hope I can count on your support for this bill. Please write back and let me know your position on this important issue."*
- Include your name and address on both the letter and the envelope or within your e-mail message.
- Target and time your letter. Representatives will give the most weight to letters from their own constituents. However, if a bill is to be heard in a particular committee or subcommittee, you may need to communicate with

the committee leadership (e.g., Chairperson of the Senate Health and Human Services Committee). In this case, explain that while you are not from the legislator's own district, you hope that the needs of all citizens will be considered in reaching a decision on the bill. Naturally, timing the letter before a vote is taken is critical.

- Follow up by thanking your representative when his/her actions support your position.

Where to Write:

U.S. Congress

The Honorable _____
senate.gov/senators/contact/

Dear Senator (name):

House of Representatives

The Honorable _____
house.gov/representatives/

Dear Representative (name):

California State Legislature

Senate

The Honorable _____
senate.ca.gov/senators

Dear Senator (name):

Assembly

The Honorable _____
assembly.ca.gov/assemblymembers

Dear Assembly Member (name):

Make a Phone Call:

When time is of the essence, a phone call can be a practical way to express your concern to an elected representative. The most effective calls are to the Capitol offices, particularly when a vote is imminent.

- Introduce yourself and give your affiliation if you are working on behalf of a particular group, organization or campaign. Be sure to mention if you are a constituent.
- Do not expect to speak to your representative directly. Most likely, you will speak to a receptionist or legislative staff. These individuals are responsible for keeping the legislator informed.
- Explain why you are calling. Example: *"I'm calling to register my opposition to the proposed budget cuts for adult day care centers. Please be sure that the Assemblyman is informed of my concern."*
- You may need to communicate your position to a committee that is hearing a bill or budget item. If you are not sure of the committee name or hearing schedule, you can ask staff members at your own representative's office.
- Where to Phone: **U.S. Capitol Switchboard** Washington DC, (202) 244-3121. The operator will refer you to any U.S. Senator or U.S. Representative (congressman/woman). In California, The **Chief Clerk of the Assembly** can help you reach any Assembly member by calling (916) 445-3614. The **Secretary of the Senate** will provide phone numbers for any California State Senator (916) 445-4251.
- Faxing is also an effective way of sending your letter to a legislator. All state legislators and members of Congress have fax machines.

Fax numbers can be obtained from the same sources as legislative and Congressional telephone numbers (see “Where to Phone” above).

Visit Your Elected Representative:

Meeting face-to-face with a legislator or designated staff is an excellent way to establish a relationship and convey your point of view.

- State legislators often go home to their district offices on Thursday or Friday. Meetings at the State Capitol are best set for Tuesday or Wednesday.
- Congressional representatives in Washington, D.C. are more likely to come home on the weekend or on extended holidays or periods of Congressional recess. Contact the Capitol office to determine the best time to make an appointment.
- Plan ahead. Legislators’ schedules fill up weeks in advance. Plan your first visit before there’s a “crisis” to establish a friendly rapport.
- Do not set your hopes on meeting with your representative in person. Legislators are busy and schedules often change at the last minute. An effective meeting can be held with a legislative staff aide (often the very people who craft legislation or brief their supervisors on important issues).
- When you call the office, ask to speak to the scheduler. Introduce yourself, explain the nature of the visit, give the names and number of other persons who will come

along on the visit, how long you will need (15 to 30 minutes), and when you would like to visit. You may be asked to send a request in writing.

- After an appointment has been scheduled, it is wise to confirm the information by physical mail, e-mail, or phone (correspondence should be addressed to the legislator, even if the meeting is scheduled with staff).
- If scheduling more than one meeting at the Capitol in one day, leave 30 minutes in between appointments to get from one room to another. In Sacramento, some legislative offices are located outside the Capitol.
- Do your homework by learning something about the person you will visit. Rehearse what you will say, keeping in mind the legislator’s background and interests. You may wish to begin by sharing your own personal caregiver story. Show your knowledge by mentioning any action taken or bills authored/supported by the legislator in a similar area, if appropriate.
- Be clear about the purpose of the meeting. Example: *“I am here today to help familiarize you with the needs of family caregivers,”* or *“I would like to know if I can count on your support for improving the quality of care in nursing homes.”*
- Add your voice to others who share similar concerns by joining a larger group or organization going to visit the Capitol. This

way you can coordinate with existing efforts and increase your clout.

- Understand that current fiscal constraints make it difficult to advocate for increased funding for programs and services. Do not apologize for this fact. Instead, be clear about the importance of a program or service to you and your family. Example: *“I know funding is tight and not everything can be considered a priority, but I am here to tell you what is a critical issue for me and others like me.”*
- Bring a few brief written materials, if available, to leave in the office which relate to the purpose of your visit.
- Bring a camera. Even if a legislator cannot meet with you in person, he/she may be pulled out of a meeting momentarily for a photo opportunity.
- Remember to thank the legislator or staff for your meeting. It is also a good idea to send a thank you letter or e-mail message addressed to the legislator.

Other Activities

- Stay informed. There are a number of organizations that monitor legislative activities at either the state or the federal levels. Newsletters and other publications can keep you up-to-date (see the Resources listed at the end of this fact sheet for agency names and addresses).
- Contribute your ideas and energy by joining a committee, task force, or campaign. Such groups may

work on a single issue or a variety of issues. Tasks might include organizing a public event or drafting policy recommendations. Even if you do not attend committee meetings, you can still lend your support to a letter writing campaign or telephone tree.

- Write a letter to the editor or opinion editorial op-ed piece stating your views in your local newspaper. This is an excellent sounding board to help educate the public about a cause.
- Testify at a hearing. Legislative and Congressional committees often hold hearings to gather support and expert opinions while drafting legislation. Family caregivers can provide compelling stories of their daily struggle in caring for a loved one. Be sure to contact the committee the day of the hearing; last minute schedule changes occur frequently.
- All federal bills can be searched and downloaded at congress.gov. You can also request copies of bills from your representative. California bills are available at leginfo.legislature.ca.gov.

Selected Advocacy Resources

Alzheimer’s Association

www.alz.org

AARP

www.aarp.org

Families USA

www.familiesusa.org

The National Consumer Voice for Quality Long- Term Care

www.theconsumervoice.org

Justice in Aging

www.justiceinaging.org

National Committee to Preserve Social Security and Medicare

www.ncpssm.org

OWL – The Voice of women 40+

www.owl-national.org

California Organizations:

California Advocates for Nursing Home Reform (CANHR)

www.canhr.org

Center for Health Care Rights

www.healthcarerights.org

Disability Rights Education and Defense Fund (DREDF)

www.dredf.org

Health Access California

www.health-access.org

Resources

Southern Caregiver Resource Center

891 Kuhn Drive, Ste. 200

Chula Vista, CA 91914

(858) 268-4432 | (800) 827-1008 (in CA)

E-mail: scrc@caregivercenter.org

Website: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions and is for residents of San Diego and Imperial

counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance National Center on Caregiving

(415) 434-3388 | (800) 445-8106

Web Site: www.caregiver.org

E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

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