



Del Mar Caregiver Resource Center  
*A program of Health Projects Center*

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## Fact Sheet

# Advocacy Tips for Caregivers

### A Call to Action

Families—not institutions—provide the majority of care to chronically ill and disabled loved ones. 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 experience 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 are effective methods 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 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

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**Health Projects Center's  
Del Mar Caregiver Resource Center**  
Serving Monterey, San Benito and Santa Cruz Counties

(831) 459-6639  
Toll Free: 1-800-624-8304

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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 \_\_\_\_\_  
U.S. Senate  
Washington, DC 20515  
[www.senate.gov](http://www.senate.gov)

The Honorable \_\_\_\_\_  
House of Representatives  
Washington, DC 20510  
[www.house.gov/writerep/](http://www.house.gov/writerep/)

#### **California State Legislature**

The Honorable \_\_\_\_\_  
State Capitol  
Sacramento, CA 95814

The Honorable \_\_\_\_\_  
State Capitol  
Sacramento, CA 95814

### **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.
- Don't 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 which is hearing a bill or budget

item. If you are not sure of the committee name or hearing schedule, you can ask staff at your own representative's office.

- **Where to Phone: 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 **Assembly Chief Clerk** can help you reach any Assembly member (916) 445-3614. The **Senate Secretary** 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, DC 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 bosses 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 people who will come along on the visit, how long you will need (15 to 30 minutes), and when you would like to come. You may be asked to send a request in writing.
- After an appointment has been scheduled, it is wise to confirm the information by mail, e-mail or phone (correspondence should be addressed

to the legislator him/herself, even if the meeting is scheduled with staff).

- If scheduling more than one meeting at the Capitol in one day, leave 30 minutes 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 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 addressed to the legislator.

## Other Activities

- Stay informed. There are a number of organizations which 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: join 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 don't 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 news-paper. 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 struggles 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 from the Library of Congress [TOMAS](#) website. You can also request copies of bills from your representative. California bills are available at the Legislative Council of California's [Legislative Information](#) website.

## Selected Advocacy Resources

### National Organizations

#### **Alzheimer's Association**

225 N. Michigan Avenue, Floor 17  
Chicago, IL 60601-7633  
(800) 272-3900  
(local chapters throughout the U.S.)

#### **AARP**

601 E. Street, NW  
Washington, DC 20049  
(888) 687-2277

#### **Families USA**

1201 New York Avenue, NW  
Washington, DC 20005  
(202) 628-3030

#### **Family Caregiver Alliance**

*National Center on Caregiving*  
180 Montgomery Street, Suite 1100  
San Francisco, CA 94104  
(415) 434-3388 or (800) 445-8106

**National Citizen's Coalition for Nursing Home Reform**

1828 L. Street, NW, Suite 801  
Washington, DC 20036  
(202) 332-2275

**National Senior Citizens' Law Center**

1101 – 14th Street, NW, Suite 400  
Washington, DC 20005  
(202) 289-6976

**National Committee to Preserve Social Security and Medicare**

10 G Street, NE, Suite 600  
Washington, DC 20004  
(800) 966-1935

**California Organizations**

**California Advocates for Nursing Home Reform (CANHR)**

650 Harrison Street, 2nd Floor  
San Francisco, CA 94107  
(415) 974-5171  
(800) 474-1116 for consumers

**Center for Health Care Rights**

520 S. Lafayette Park Place, Suite 214  
Los Angeles, CA 90057  
(800) 824-0780 (in LA only) or (213) 383-4519

**Disability Rights Education and Defense Fund (DREDF)**

2212 Sixth Street  
Berkeley, CA 94710  
(800) 348-4232 or (510) 644-2555

**Health Access California**

1127 11th Street, Suite 234  
Sacramento, CA 95814  
(916) 497-0923  
(Also in Oakland and Los Angeles)

**Resources**

**MONTEREY COUNTY**

**Health Projects Center's**

**Del Mar Caregiver Resource Center**

(831) 424-4359

Web site: <http://www.delmarcaregiver.org>

**SANTA CRUZ COUNTY**

**Health Projects Center's**

**Del Mar Caregiver Resource Center**

(831) 459-6639

Web site: <http://www.delmarcaregiver.org>

**SAN BENITO COUNTY**

**Health Projects Center's**

**Del Mar Caregiver Resource Center**

(831) 459-6639

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Del Mar Caregiver Resource Center supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

For residents of Central California, Monterey, Santa Cruz and San Benito Counties, Del Mar CRC provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating brain disorders that strike adults.

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San Francisco, CA 94104  
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(800) 445-8106

Web Site: [www.caregiver.org](http://www.caregiver.org)

E-mail: [info@caregiver.org](mailto:info@caregiver.org)

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

FCA's [National Center on Caregiving](#) offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

FCA's e-newsletter, [Caregiving PolicyDigest](#), offers up-to-date information on national policy issues.

*Reviewed by Burns Vick, Jr., J.D., Vick & Associates, Sacramento, California. Prepared by Family Caregiver Alliance in cooperation with California's Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of adults with chronic health conditions. Funded by the California Department of Mental Health. © 1998 Family Caregiver Alliance. Revised 2007. All rights reserved.*