

Redwood Caregiver Resource Center
1140 Sonoma Av., Ste 1B
Santa Rosa, CA 95405
(707) 542-0282 or (800) 834-1636
Fax (707) 542-0552

Email: rcrc@redwoodcrc.org

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Fact Sheet **Advocacy Tips** **for Caregivers**

A Call to Action

Families provide the majority of care to chronically ill and disabled loved ones living at home. These families know the enormity of the burden in caring for someone with Alzheimer's or Parkinson's diseases, stroke, head injury, HIV dementia, or other cognitive impairment, and the challenge in locating appropriate assistance and services. Personal experiences with service 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 hints and tips for effective strategies for families to get involved in state or federal advocacy efforts.

How Families Can Help Effect Change at the Public Policy Level

Write a letter to your elected representative.

Representatives rely on letters from their constituents to keep them informed and to know where constituents stand on critical or controversial issues.

- Write legibly or type your letter and try to keep your communication to one brief page. A personal letter is more effective than a post card.
- Include your name and address on both the letter and the envelope.

- Make your letter 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."*
- 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 (i.e., 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 Californians 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
Internet: www.house.gov

Dear Senator (name):

The Honorable _____
House of Representatives
Washington, DC 20510
Internet: www.senate.gov

Dear Representative (name):

California State Legislature

The Honorable _____
State Capitol
Sacramento, CA 95814

Dear Senator (name):

The Honorable _____
State Capitol
Sacramento, CA 95814

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.
- 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 at the California State Capitol, you can ask your own representative's office to check the Senate or Assembly *daily file*.

- 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). 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.
- A note on FAXing: All state legislators and members of Congress have FAX machines. FAXes are beginning to replace telegrams as an expedient way to contact legislators. 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 boss 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 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 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 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 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 (with a flash). 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 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 author or committee the day of the hearing; last minute schedule changes occur frequently.
- Free copies of up to six **federal bills** (S___ for Senate bills) can be ordered from: the Senate Document Room, Rm. B-04 Hart Bldg., Washington, DC 20510-7106 or (HR___ for House bills) the House Document Room, Rm. B18 Ford Bldg., Washington, DC 20515-6620.
- A **California state bill** can be requested free from an Assembly member or Senator's district office. Or you can order from the Capitol Bill Room, Room B-32, State Capitol, Sacramento, CA 95814. You must know the bill number (AB___ for the Assembly and SB___ for the Senate). Enclose a self-addressed return label or envelope with your request.

Selected Advocacy Resources

California Organizations

California Advocates for Nursing Home Reform
(CANHR)

1610 Bush Street
San Francisco, CA 94109
(415) 474-5171
www.canhr.org

Disability Rights Education and Defense Fund
(DREDF)

2212 Sixth Street
Berkeley, CA 94710
(800) 466-4ADA or (510) 644-2555
www.dredf.org

Family Caregiver Alliance

425 Bush Street, Suite 500
San Francisco, CA 94108
(415) 434-3388 or (800) 445-8106 (in CA only)
www.caregiver.org/policy.html

Health Access

942 Market Street, Suite 402
San Francisco, CA 94102
(415) 395-7959

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

Pacific Disability and Business Technical
Assistance Center

2168 Shattuck Avenue, Suite 301
Berkeley, CA 94704
(800) 949-4232
www.pacdbtac.org

National Organizations

Alzheimer's Association

919 N. Michigan Avenue, Suite 1000
Chicago, IL 60611-1676
(800) 272-3900
Internet: www.alz.org
(local chapters throughout the U.S.)

American Association of Retired Persons (AARP)

601 "E" Street, N.W.
Washington, DC 20049
(202) 434-2277
Internet: www.aarp.org

Families USA Foundation

1334 "G" Street, N.W.
Washington, DC 20005
(202) 628-3030
Internet: www.familiesusa.org

Gray Panthers

2025 Pennsylvania Ave. NW, Suite 821
Washington, DC 20006
(202) 466-3132
(local chapters throughout the U.S.)

Long-Term Care Campaign

P.O. Box 27394
Washington, DC 20038
(202) 434-3744

National Citizen's Coalition for Nursing
Home Reform

1424 – 16th Street, N.W., Suite 202
Washington, DC 20036
(202) 332-2275

National Senior Citizens' Law Center

1101 – 14th Street, N.W., Suite 400
Washington, DC 20005
(202) 289-6976
Internet: www.nclc.org
or
2639 La Cienega Boulevard
Los Angeles, CA 90034
(310) 204-6015

Resources

Family Caregiver Alliance
425 Bush Street, Suite 500
San Francisco, CA 94108
(415) 434-3388
(800) 445-8106 (in CA)
Web Site: <http://www.caregiver.org>
E-mail: info@caregiver.org

FCA's information Clearinghouse covers current medical, social, public policy and caregiving issues related to brain impairments.

For residents of the greater San Francisco Bay Area, FCA 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.

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 brain-impaired adults. Funded by the California Department of Mental Health. Revised and reprinted January 1998. ©All rights reserved.