



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

---

## **Fact Sheet**

# **How to Form a Support Group for Caregivers of Brain Impaired Adults**

Support or "self-help" groups are formed by individuals who share common concerns. The groups may be participant-initiated or provided by a health care institution, social services agency, or nonprofit organization.

The purpose of a support group is to allow persons who are facing the difficult task of daily caregiving to benefit from interaction and support from other people in a similar situation.

A degenerative or terminal illness, or an accident involving a family member, is a traumatic experience for spouse, parents, children and other relatives. A support group may work towards mutual problem-solving, coping mechanisms, dealing with grief and sharing information. Some communities have a network of established support groups; others may have few or none. The following guidelines will assist family members or caregivers interested in forming a support group.

### **Guidelines for Establishing a Family Support Group**

#### **Getting Started**

- Determine the focus of your group (i.e. family members of Alzheimer's victims, stroke survivors, bereaved relatives...).
- 
- Establish a contact person whose phone number can be used.
- Enlist the help of other families in a similar situation, if you know any.
- Seek assistance from medical experts, social workers, or other clinicians who can provide consultation and meeting space, give presentations or facilitate meetings. Good initial contacts may be obtained from existing support groups, nursing homes, hospitals, family physicians, neurologists, counseling and home care services, Adult Day Care programs, senior centers, and local branches of national organizations such as the American Heart Association, the Alzheimer's Association, or the National Head Injury Foundation. Make sure to leave your name, address, and phone number when contacting professionals or agencies so that they can make referrals to your group.

---

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

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

[www.delmarcaregiver.org](http://www.delmarcaregiver.org)

- Plan a time, place and agenda for the first group meeting.
- Advertise the group by distributing press releases to local newspapers and by posting announcements on community bulletin boards in churches and synagogues, libraries, clinics and senior centers. You may want to design an eye-catching flier.
- Try to get a human interest story into the media to help focus community awareness on the problems and to locate families in need of support.
- Talk to local radio and TV stations. You can submit 30-second and one minute public service announcements which are typewritten. There is no charge for nonprofit organizations. Announcements should describe the nature of the support group, the time, place and phone contact for meetings.

## Structure, Goals, Objectives, and Group Process

The group must determine certain procedural and philosophical matters, including:

- How often should the group meet?
- What times are convenient?
- Is the meeting site accessible?
- Who will lead/facilitate the sessions? (It is helpful, especially in the beginning, if a professional can lead the group or at least make a presentation.)
- Discuss with other participants what they want to get out of the group and how participants might help one another.
- Plan long-term goals: Will the group be used as a vehicle to promote public awareness, to seek out isolated individuals who might like to participate, or will the group concentrate on building rapport among a tight-knit group of members?
- Plan future agendas: Local agencies, national organizations, universities, and public libraries are all potential sources of information. There may be books, films, video tapes, and research articles available for loan that you can share with the group and/or use as a topic of discussion.

## Recommended Readings

*Starting a Self-Help Group for Caregivers of the Elderly*, Louise Fradkin, et al., 1993, Children of Aging Parents, Woodburn Office Campus, 1609 Woodburn Rd., Suite 302A, Levittown, PA 19057.

*Head Injury Peer Support Group Training Manual*, 1993, Family Caregiver Alliance, San Francisco, CA.

*How to Organize a Self-Help Group*, Andy Humm, The National Self-Help Clearinghouse, CUNY Graduate Center, 33 West 42nd Street, Room 1222, New York, NY 10036.

*Developing a Support Organization*, Elizabeth McKinney, 1989, Legacy Family Support Services, Good Samaritan Hospital & Medical Center, 1015 N.W. 22nd Ave., Portland, OR 97210.

*Directory of California Support Groups for Caregivers of Brain-Impaired Adults*, Family Caregiver Alliance, San Francisco, CA. Revised and reprinted annually.

## Credits

Building Your Support Group, *PWA Voice*, Fall, 1989.

Support for Caregivers of Dependent Elderly, Vicky L. Hardy and Kathryn Riffle, *Geriatric Nursing*, Vol. 14, No. 3, May-June, 1993.

When the Best Help is Self-Help, or, Everything You Always Wanted to Know About Brain Injury Support Groups, Lawrence Miller, *Journal of Cognitive Rehabilitation*, Nov.-Dec. 1992.

## 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

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

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.

### **Family Caregiver Alliance**

180 Montgomery Street, Suite 1100

San Francisco, CA 94104

(415) 434-3388

(800) 445-8106 (in CA)

Web Site: <http://www.caregiver.org>

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

Family Caregiver Alliance supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

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.

### **American Self-Help Clearinghouse**

Northwest Covenant Medical Center

25 Pocono Rd.

Denville, NJ 07834

(201) 625-7101

(201) 625-9053 (TDD)

**The Well Spouse Foundation**

601 Lexington Ave., Suite 814

New York, NY 10022-6005

(212) 644-1241

(800) 838-0879

**The National Self-Help Clearinghouse**

Graduate School and University Center of the City  
of New York

25 West 43rd Street, Rm. 620

New York, NY 10036

(212) 642-2944

These national centers have regional affiliates across  
the U.S. and in Canada. Information on  
self-help for groups of all kinds is available.

*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. Revised June 1996. Funded by the California Department of Mental Health. ©All rights reserved.*