



# Organizing Family Councils in Long Term Care Facilities

**CANHR**

*Long Term Care Justice and Advocacy*

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# Introduction

## Family Councils: Avenues for Change

### The Law:

California's Family Council bill, Health & Safety Code §1418.4, went into effect on January 1, 1989, and was amended by SB 1551 (Dunn), which was signed by the Governor and became effective January 1, 2000. California's family council law now provides the following:

- Defines Family Council as a meeting of family members, friends or representatives of two or more residents to confer in private without facility staff.
- No facility may prohibit the formation of a family council when requested by a member of the resident's family or the resident's representative.

### Family Council Rights:

- The family council shall be allowed to meet in a common meeting room of the facility at least once a month during mutually agreed upon hours.
- Facilities shall in no way limit the rights of residents, family members and family council members to meet independently with outside persons or with facility personnel.
- Staff or visitors may attend family council meetings at the group's invitation.

### Facility Obligations to Family Council:

- The facility shall provide a designated staff person who shall be responsible for providing assistance and responding to written requests that result from family council meetings.
- The facility shall consider the views and act upon the grievances and recommendations of a family council concerning proposed policy and operational decisions affecting resident care and life in the facility.
- The facility shall respond in writing to written requests or concerns of the family council within 10 days.
- Family councils shall be provided adequate space on a prominent bulletin board or other posting area for the display of notices, minutes, newsletters, or other information pertaining to the operation or interest of the family council.
- When a family council exists, the facility shall include notice of the meetings in quarterly mailings and shall inform family members, friends and representatives of new residents of the time, place and date of the meetings.

### Penalties for Interference:

- No facility shall willfully interfere with the formation, maintenance or promotion of a family council. "Willful interference" includes discrimination, retaliation or the willful scheduling of facility events in conflict with a previously scheduled family council meeting.
- Violation of these laws can result in a citation and penalty up to \$1,000.

California's new family council provisions are based on the federal OBRA regulations, found at 42 CFR §483.15(c). These state and federal laws give families and friends of residents a unique opportunity to effect change.

## What are Family Councils?

Family Councils are not merely gripe sessions. While the primary purpose of a family council is for families, as a group, to influence the quality of care for the residents, they also offer a forum to enhance communications with the facility staff and offer peer support for the relatives and friends of residents.

Whatever affects the residents' lives is a proper concern of the family council, whether it's the atmosphere of the facility, the role of the medical director, the quality of day-to-day care or the activity program.

An effective family council will provide an opportunity for the members to meet without facility staff (and thus, without fear of retaliation), share concerns, and submit the group's concerns in writing to the administrator. The council should request that appropriate action be taken and follow up the request to ensure that such action was taken. The facility must respond to this request within ten days.

## Working Together for Prevention of Problems

Too often, nursing homes and residents' representatives attempt to resolve resident problems individually rather than working to prevent the problems in the first place. In addition, residents and their representatives are reluctant to assert their rights and lodge legitimate complaints for fear of retaliation. As a result, issues are not addressed in a timely manner through this one-on-one approach.

# Organizing a Family Council

By presenting a united voice with mutual goals and concerns, members need not fear being isolated and threatened, and they can address the problems of **all** residents, rather than just a few. Each family council is different, according to the needs and interests of its members. As a result, there are no hard and fast rules about organizing and running a council. However, experience has shown that the effectiveness and ongoing success of a family council has much to do with the initial organizing.

## Where to Begin

Before starting to organize a council, contact the social worker and the administrator of the home to enlighten them about family councils and to enlist their support. A presentation of the idea at a staff meeting of the nursing home would also be helpful, so that all nursing home personnel understand and do not feel threatened by a family council being started.

## Plan an initial meeting with families and friends:

- Plan a meeting to which all families and friends of the residents of the home will be invited to determine if the families are interested in having a council, and, if so, to begin the process of organizing. In some cases, the nursing home is willing to send out invitations to the families. Following up on the invitations with a personal telephone call is very effective. Notices should also be posted in the facility, because all interested family members and friends may not be included on the facility's mailing list.
- Get together a small group of families and friends who are already active and involved and work with them to plan and run the introductory meeting. This can be more time-consuming initially, but in many cases, it will be more effective because it establishes, from the start, that the council will be run by the families themselves, rather than the staff.

## The Introductory Meeting

The introductory meeting should include

- a. **Presentation:** An explanation of family councils, their purpose, importance and organization. Slide or video presentations may be used for this purpose. CANHR can provide fact sheets and the Family Council DVD for the meeting. We also offer a booklet that provides a comprehensive overview of Medi-Cal for long term care, a small claims guide for residents, and other helpful materials and advocacy tools. See our website or contact our office for more details.
- b. **Organizing:** A decision on whether or not they want a council. If the concept is explained with enthusiasm it is unlikely that there will be a negative response. However, it is important that the principle of self-determination is established by making it a group decision.
- c. **Selection of officers:** Since the families often do not know each other yet, most councils begin with temporary, volunteer officers, who serve until regular elections can be held. Most councils have a chair (or president), a vice-chair, a secretary, who will take notes during the meetings, and a treasurer. Some councils have co-chairpersons to share the duties.

Having co-chairs or alternating leadership is often a good idea. This builds leadership skills and prevents the chair from being "co-opted" by the facility and keeps the family council from becoming a "personal" agenda, rather than a group agenda. No chairperson should serve more than one year, unless there are no alternatives and he/she should not speak on behalf of the group without its permission.

## Staff Involvement

Members will often suggest that the staff run the council instead of, or until, electing officers. This has proven to be unsuccessful in most cases. A staff-run council is not a family council. In many instances where a family council has been staff-run, interest and attendance has steadily declined or the council has lapsed into a purely social group. Often a staff-run council meets infrequently or is not very active because the staff doesn't have adequate time to devote to it. In many instances, well-meaning staff persons have agreed to run a council temporarily only to find it much harder to get the family members to assume responsibility later. By selecting temporary officers at the very first meeting, many such problems can be avoided.

Although the facility is required to designate a staff liaison to provide assistance and to respond to written requests from the group, this staff person is not required to attend the meeting. In fact, staff are permitted to attend only with the consent of the council. It is important to have at least some time at each meeting where the family council members can meet in private.

## Structure

A decision should be made on what the basic structure of the family council should be. Two structures are most common:

- a. Group structure: if the group of interested families and friends is small, a council usually invites all families to each meeting. Planning, decision-making, and other basic functions are carried out in these meetings.
- b. Committee structure: if the group is large, a steering or executive committee is often selected to plan and make decisions that would be difficult or time-consuming to deal with in the full council. This committee may meet monthly, prior to the regular meeting and make reports to the full council. One of its major tasks is to plan regular meetings and projects to which all families are invited. The steering committee can include all officers, sub-committee chairpersons, representatives of each floor or wing, or a number of members elected by the whole membership. With this type of structure, it is very important that the steering committee make efforts to get input from other members and to keep other members active and involved.

# Sample

September 1, 2009

Ms. \_\_\_\_\_, Administrator  
ABCDE Convalescent Hospital

Dear Ms. \_\_\_\_\_:

On behalf of the several family members of residents, I have been asked to inform you that we are in the process of organizing a Family Council

We hope, through the Family Council, to forge a partnership with the staff that will enhance the quality of care for all residents. However, in order to get the fullest participation of families, the council meetings will be limited to families and representatives of residents, with staff and speakers present by invitation. As we would like to meet at least once a month on a Tuesday evening, between 7:00 pm and 9:00 pm, please let me know what room we could use for this purpose and where we can post notices of the meetings. We would like to hold our first meeting this month.

Of course, there will be many occasions when we hope to meet with you. As one of the purposes of the Family Council is to promote better communication with the facility, within one week of our meetings, we will submit to you a summary of the concerns discussed at our meeting. We would like to have a written response within 10 days, indicating the action, if any, you have taken, or will take on matters of concern to the family council. We would like to post both our summary and your response in the facility.

Please let me know which staff person has been designated to provide assistance and respond to the Family Council's concerns, and please contact me if you have any questions.

I look forward to working with you on behalf of all the residents.

Sincerely,

Photocopy to:

1. \_\_\_\_\_, Ombudsman
2. CANHR

# Sample

## Example of Minutes for a Family Council Meeting

The ABCDE Nursing Home Family Council met Tuesday, September 2, 2009, at 2 p.m. and was chaired by Co-Chair Mary L \_\_\_\_\_.

### Agenda:

1. Introductions

2. Announcements (Home s luncheon Sept. 29)

3. Administrator s response to concerns from Aug.11, 2009 meeting:

fëAssistance with feeding: DON has re-scheduled staff to help feed patients.

fëLoss of items: Forms for reporting loss will be mailed to families. Dentist to engrave dentures Feb. 2. More procedures being developed. Will have info. next month.

fëWed. a.m. Art Class: Time changed to 10:30 so more residents can attend.

4. New Business

a. Concerns:

fëSeveral families agreed that their relatives need pills crushed and that it s not done consistently. It was agreed to request DON to make a survey of patients.

fëAre families phone numbers up-to-date in of ce? Request Administrator to up-date by mail.

b. Volunteers for New Families Welcoming Comm. for Oct.: J. Cohen; L. Jones.

c. Discussion re: assistance with eating. Families agreed that new scheduling is meeting needs of all residents.

d. Unanimous vote: Letter to Assemblyman \_\_\_\_\_ supporting AB 000.

e. Will try to get speaker from Licensing or a geriatric physician for March.

f. Oct. mtg of Family Council will be addressed by panel of aides.

Richard \_\_\_\_\_, Acting Secretary

## Sample

### Family Council Recommendations from 9/2/09 Meeting

(The following are only brief extracts and the full notes should be read to ensure that full knowledge of the problems is obtained.)

Area Discussed	Family Council Recommendations	Actions Taken by Dept. Heads	Completion Date
Patients able to converse should be seated together at meals.	As stated.		
Walking program.	Institute previously discussed program.		
Patient bedtimes.	Implement + <u>enforce</u> better bedtime policy.		
Wrapping sheets around legs.	Issue reminder and/or training.		
Noisy patients.	Place noisy patients together so quiet ones can sleep.		
Extra liquids in warm weather.	Extra servings of water handed to patients who can't or won't get for themselves. Families will assist.		



# Tips for Organizing an Effective Family Council

## Meet With the Administrator

When you and other family members or friends decide to start a Family Council, request a meeting with the Administrator to discuss the date(s), a mutually agreed upon time, the place where you can post notices, the designated staff liaison and the process for submitting and responding to concerns of the Family Council (see sample letter to administrator). You don't need the cooperation of the Administrator, but it helps if you want to reach out to other family members and new ones, and if you really want to see changes rather than resistance. In addition, it's better to start out on a cooperative basis, as things tend to heat up soon enough. If the Administrator won't discuss it, send a letter and start the Family Council without his/her cooperation. They are prohibited from interfering with the organization of Family Councils.

## Involve Facility Staff

Facility staff often feel threatened by Family Councils. They see them as gripe sessions that separate family members from the staff. While Family Councils, by necessity, have to allow for family members to gripe and voice their concerns, this should be done during the private council meeting. While at least some part of every meeting should allow for the Family Council to meet in private, staff should be invited to certain meetings with an allotted amount of time to discuss specific concerns. For example, if one of the council's concerns involves dietary issues, invite the dietician to talk to the council, answer questions and address these concerns. It's always better to have the staff on your side, if possible, since they are the ones who provide the direct care.

## Put It in Writing

Someone should take notes during the meeting and be responsible for relaying the specific concerns of the family council in writing to the administrator or the staff liaison. The issues and/or concerns should be agreed upon at the end of the meeting, and the format and tone of conveying the message should be agreed upon. If you don't put it in writing, don't expect a timely response. Be concise and direct. Be specific and give examples of the problem, without naming residents' names.

## Pick Your Battles

Family Councils usually form because of a serious problem(s) at a facility. Thus, the family members and friends who initially get involved are usually pretty upset by the time of the first meeting. However, it would be a good tactic to lay out all of the issues and prioritize. Pick one or two less serious issues first, and see how the Administrator responds. Or pick the one issue that has the most direct effect on the residents. Then you'll know what you're up against, and you'll have an idea of the type of challenge that lies ahead. It's also unrealistic to expect all of your concerns to be dealt with at once. At the end of each meeting, one or two concerns should be submitted in writing, with suggestions, if appropriate, as to how the concerns could be addressed.

## Do Your Homework

Find out the laws and regulations regarding the particular issue or issues the family council selects. If you don't know your rights or the residents' rights, you won't know if the response is appropriate or not. (Call CANHR for a copy of current state and federal regulations regarding the issue or issues)

## Prepare an Agenda

Although some time needs to be set aside for free discussion of concerns, the meetings should have

some structure. You don't need Robert's Rules, but you should have a plan for each meeting. For example, there should be time for introductions of all attendees, follow-up from the last meeting, guest speakers, if any, and setting the time and dates of the next meetings at a convenient time for as many as possible.

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With the exception of making sure you put all correspondence from the Family Council in writing, the meetings should not be too formal. They should be a place where family members, representatives of residents and the residents can feel free to talk about what they need to talk about; where they can give and get emotional support and important information; and where they feel welcome. Have some refreshments. Nothing increases attendance like the smell of fresh baked chocolate chip cookies! Some facilities will provide cookies, coffee and soft drinks, but don't count on it. Bring your own or take turns bringing refreshments.

### Involve the Residents

Invite any residents who can or want to attend. Sometimes, family members will bring the residents to the meetings. That way they can combine their visits with the meeting. Most residents probably won't want to attend, but make them welcome. Their voices are the ones that seldom get heard.

### Reach Out!

One of the first orders of business for a Family Council should be organizing an outreach program at the facility to make sure all the current family members and the new ones know about the meetings. If the administration is cooperative, your job will be easy. That is not always the case, however, and you'll need to be innovative in meeting family members. Have special, short get-togethers on a weekend. Bake some cakes and have coffee. If you can't continue to get new family members involved, the Family Council won't last.

### Try Not to Control

A lot of family councils fail because the person who organized it, put in all the time and energy and took control, doesn't want to give up control. This is a difficult dilemma and requires a careful balance of addressing members' real fear of retaliation and empowering them at the same time. The only way you can do this is by letting them talk, educating them and showing them, through results, that Family Councils can be effective tools for improving care. Change in leadership can be healthy, as long as the leader is in sync with the Family Council's and residents' concerns.

## Suggested Activities of Family Councils

f) Monthly meetings, run by families, with some portion of the meeting limited to families only, for discussion of problems. Providing information, through speakers and newsletters, about:

- a. California nursing home regulations;
- b. the Ombudsman Program;
- c. nursing home inspections;
- d. the duties of the home's staff;
- e. financial planning;
- f. pending nursing home legislation;
- g. how to file complaints with Licensing;
- h. emotional aspects of having a relative in a nursing home;
- i. Medi-Cal eligibility and coverage;
- j. community resources.

f) Welcoming new residents and families. Helping with orientation.

f) Volunteering in the nursing home.

## Community Resources

There are numerous community organizations who will provide written information to distribute at the meetings, and who may provide speakers. CANHR staff is also available to assist with initial organizing efforts and suggestions for speakers. The following is a brief list of community resource groups who may be able to provide speakers, literature, and information for both family councils and individuals. Please call CANHR for resources on specific issues or problems.

Long Term Care Ombudsman provides trained, supervised volunteers who visit nursing homes and residential care facilities for the elderly, and who can advocate on behalf of residents, investigate complaints and help to resolve problems if possible. Ombudsman programs are available for every county.

Caregiver Resource Center provides information and referral services, counseling, support groups, education, training and other resources to caregivers of brain impaired adults. Fact sheets and other materials available. There are eleven centers throughout the state.

Alzheimer's Association provides support and assistance to affected persons and their families; sponsors caregiver and family support groups in most counties; numerous publications available. There are twelve branches throughout the state.

National M.S. Society provides information and referral, support and assistance for persons with Multiple Sclerosis and their families. Some centers have publications available which could be of use in educating nursing home staff about M.S. There are eight chapters throughout the state.

**CANHR:**

1616 S. Main Street, Suite 100, San Jose, CA 95128

**California Dept. of Public Health Nursing Home Complaints:**

1616 S. Main Street, Suite 100, San Jose, CA 95128

**Long Term Care Ombudsman:**

1616 S. Main Street, Suite 100, San Jose, CA 95128

**Caregiver Resource Center:**

1616 S. Main Street, Suite 100, San Jose, CA 95128

**Alzheimer's Association:**

1616 S. Main Street, Suite 100, San Jose, CA 95128

**National Multiple Sclerosis Society:**

1616 S. Main Street, Suite 100, San Jose, CA 95128

**Keep in Touch!**

If you are just organizing a family council, or if your family council has had an interesting challenge or victory, please contact CANHR. We try to print letters and articles by members of family councils throughout California in our newsletter, The CANHR Advocate. By pooling information and sharing experiences and techniques, we can help to enhance the lives of all of California's nursing home residents!

## California Codes Health and Safety Code

§1418.4. Family councils; formation not prohibited; meeting facilities; meetings with outside

- (a) No licensed skilled nursing facility or intermediate care facility may prohibit the formation of a family council, and, when requested by a member of the resident's family or the resident's representative, the family council shall be allowed to meet in a common meeting room of the facility at least once a month during mutually agreed upon hours.
- (b) Facility policies on family councils shall in no way limit the right of residents, family members, and family council members to meet independently with outside persons, including members of nonprofit or government organizations or with facility personnel during nonworking hours.
- (c) Family council for the purpose of this section means a meeting of family members, friends, or representatives of two or more residents to confer in private without facility staff.
- (d) Family councils shall also be provided adequate space on a prominent bulletin board or other posting area for the display of meeting notices, minutes, newsletters, or other information pertaining to the operation or interest of the family council.
- (e) Staff or visitors may attend family council meetings, at the group's invitation.
- (f) The facility shall provide a designated staff person who shall be responsible for providing assistance

and responding to written requests that result from family council meetings.

- (g) The facility shall consider the views and act upon the grievances and recommendations of a family council concerning proposed policy and operational decisions affecting resident care and life in the facility.
- (h) The facility shall respond in writing to written requests or concerns of the family council, within 10 working days.
- (i) When a family council exists, the facility shall include notice of the family council meetings in at least a quarterly mailing, and shall inform family members or representatives of new residents who are identified on the admissions agreement, during the admissions process, or in the resident's records, of the existence of the family council. The notice shall include the time, place, and date of meetings, and the person to contact regarding involvement in the family council.
- (j) No facility shall willfully interfere with the formation, maintenance, or promotion of a family council. For the purposes of this subdivision, willful interference shall include, but not be limited to, discrimination or retaliation in any way against an individual as a result of his or her participation in a family council, or the willful scheduling of facility events in conflict with a previously scheduled family council meeting.
- (k) (1) Violation of the provisions of this section shall constitute a violation of the residents' rights.  
(2) Violation of the provisions of this section shall constitute a class B violation, as defined in Section 1424.

## **Federal Regulations relating to Family Councils: Sec. 483.15**

A facility must care for its residents in a manner and in an environment that promotes maintenance or enhancement of each resident's quality of life.

- (a) *Dignity.* The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality.
- (b) *Self-determination and participation.* The resident has the right to ≠
  - (1) Choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care;
  - (2) Interact with members of the community both inside and outside the facility; and
  - (3) Make choices about aspects of his or her life in the facility that are significant to the resident.
- (c) *Participation in resident and family groups.*
  - (1) A resident has the right to organize and participate in resident groups in the facility;
  - (2) A resident's family has the right to meet in the facility with the families of other residents in the facility;
  - (3) The facility must provide a resident or family group, if one exists, with private space;
  - (4) Staff or visitors may attend meetings at the group's invitation;
  - (5) The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings;
  - (6) When a resident or family group exists, the facility must listen to the views and act upon the grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility.
- (d) *Participation in other activities.* A resident has the right to participate in social, religious, and community activities that do not interfere with the rights of other residents in the facility.
- (e) *Accommodation of needs.* A resident has the right to ≠
  - (1) Reside and receive services in the facility with reasonable accommodation of individual needs and preferences,

- except when the health or safety of the individual or other residents would be endangered; and
- (2) Receive notice before the resident's room or roommate in the facility is changed.
- (f) *Activities.*
- (1) The facility must provide for an ongoing program of activities designed to meet, in accordance with the comprehensive assessment, the interests and the physical, mental, and psychosocial wellbeing of each resident
- (2) The activities program must be directed by a qualified professional who ≠
- (i) Is a qualified therapeutic recreation specialist or an activities professional who ≠
- (A) Is licensed or registered, if applicable, by the State in which practicing; and
- (B) Is eligible for certification as a therapeutic recreation specialist or as an activities professional by a recognized accrediting body on or after October 1, 1990; or
- (ii) Has 2 years of experience in a social or recreational program within the last 5 years, 1 of which was full-time in a patient activities program in a health care setting; or
- (iii) Is a qualified occupational therapist or occupational therapy assistant; or
- (iv) Has completed a training course approved by the State.
- (g) *Social Services.*
- (1) The facility must provide medically related social services to attain or maintain the highest practicable physical, mental, and psychosocial wellbeing of each resident.
- (2) A facility with more than 120 beds must employ a qualified social worker on a full-time basis.
- (3) Qualifications of social worker. A qualified social worker is an individual with ≠
- (i) A bachelor's degree in social work or a bachelor's degree in a human services field including but not limited to sociology, special education, rehabilitation counseling, and psychology; and
- (ii) One year of supervised social work experience in a health care setting working directly with individuals.
- (h) *Environment.* The facility must provide ≠
- (1) A safe, clean, comfortable, and homelike environment, allowing the resident to use his or her personal belongings to the extent possible;
- (2) Housekeeping and maintenance services necessary to maintain a sanitary, orderly, and comfortable interior;
- (3) Clean bed and bath linens that are in good condition;
- (4) Private closet space in each resident room, as specified in §483.70(d)(2)(iv) of this part;
- (5) Adequate and comfortable lighting levels in all areas;
- (6) Comfortable and safe temperature levels. Facilities initially certified after October 1, 1990 must maintain a temperature range of 71-81 [degrees]F; and
- (7) For the maintenance of comfortable sound levels.

## **Guidance to Surveyors for Long Term Care Facilities**

F243

### **§483.15(c) Participation in Resident and Family Groups**

- (1) A resident has the right to organize and participate in resident groups in the facility;
- (2) A resident's family has the right to meet in the facility with the families of other residents in the facility;
- (3) The facility must provide a resident or family group, if one exists, with private space;
- (4) Staff or visitors may attend meetings at the group's invitation;
- (5) The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings;

**SEE INTERPRETIVE GUIDANCE FOR §483.15(c) AT TAG F244**

## F244

§483.15(c)(6) When a resident or family group exists, the facility must listen to the views and act upon the grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility.

### Interpretive Guidelines §483.15(c)

This requirement does not require that residents organize a residents or family group. However, whenever residents or their families wish to organize, facilities must allow them to do so without interference. The facility must provide the group with space, privacy for meetings, and staff support. Normally, the designated staff person responsible for assistance and liaison between the group and the facility's administration and any other staff members attend the meeting only if requested.

A resident's or family group is defined as a group that meets regularly to:

- Discuss and offer suggestions about facility policies and procedures affecting residents' care, treatment, and quality of life;
- Support each other;
- Plan resident and family activities;
- Participate in educational activities; or
- For any other purpose.

The facility is required to listen to resident and family group recommendations and grievances. Acting upon these issues does not mean that the facility must accede to all group recommendations, but the facility must seriously consider the group's recommendations and must attempt to accommodate those recommendations, to the extent practicable, in developing and changing facility policies affecting resident care and life in the facility. The facility should communicate its decisions to the resident and/or family group.

### Procedures §483.15(c)

If no organized group exists, determine if residents have attempted to form one and have been unsuccessful, and, if so, why.

## F245

### §483.15(d) Participation in Other Activities

A resident has the right to participate in social, religious, and community activities that do not interfere with the rights of other residents in the facility.

### Interpretive Guidelines §483.15(d)

The facility, to the extent possible, should accommodate an individual's needs and choices for how he/she spends time, both inside and outside the facility.

Ask the social worker or other appropriate staff how they help residents pursue activities outside the facility.

