

Organizing
Independent Family Councils
In
Nursing Homes

Organizing Independent Family Councils In Nursing Homes

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INDEPENDENT FAMILY COUNCILS

AVENUE FOR CHANGE

What are “Independent” Family Councils?

“Independent” family councils (managed by family/friends/representatives of residents) provide members with confidentiality and an avenue for advocacy - as intended by federal and state laws. “Facility” family councils (managed by a staff member) can be helpful, but do not provide members with the opportunity for sharing serious concerns in private or advocating for change.

Independent family councils are formed and managed by families, friends, and representatives of nursing home residents to work as a group primarily to influence the quality of care for the residents. Family councils 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 day-to-day care of the residents, the atmosphere of the facility, the role of the medical director, or activity programs.

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 can request that appropriate action be taken and follow up to ensure that such action was taken.

An “Independent” Family Council ...

- Is committed to improving the quality of care and quality of life of all residents in a nursing home.
- Includes family, friends and others who currently or previously have had a loved one in a nursing home.
- Is a strong, collective voice of concerned advocates working for positive change.

**The size of the Family Council is not important,
but commitment is!**

Family Council goals include ...

- **Advocating** for residents.
- **Supplementing** activities programs.
- **Running** staff recognition events.
- **Supporting** members in the long-term care experience.
- **Educating** members on long-term care issues.

Federal and Massachusetts Family Council (FC) Regulations

Summary

(See page 15 for full text.)

Massachusetts is the third state in the nation to enact state family council (FC) legislation. The law, effective July 1, 2004, expands upon federal legislation to further strengthen the ability of nursing home FCs to advocate for residents. The law incorporates federal regulations and adds new FC rights and facility responsibilities, as well as penalties for non-compliance. There was a major revision to federal nursing home regulations in September 2016 which, as noted below, affected certain FC rights and facility responsibilities to FCs.

Family Council (FC) Rights:

Incorporates federal law:

- FC have the right to meet in private; staff, visitors, or other guests may attend only at the council's invitation.

Additional federal rights as of September 2016:

- The resident has a right to participate in a FC.
- The resident (previously "resident's family") has right to have family member(s) or other representative(s) (representative added in 2016) meet with other families/resident representatives in the facility.
 - ✓ Family members are still permitted to organize a FC, but it is now the resident who has the right to have his/her family member or representative meet with the FC, rather than the family having this right as was the case in the prior regulations. As an example, there may be situations where a resident would not want to allow a family member, such as an estranged spouse, to join the FC.

Additional MA FC rights:

- Rights of family members are extended to friends and representatives of nursing home residents.
- Right to accept help from an organization or individual outside of the facility.
- Right to receive mail delivered to the facility; unopened to a designated contact.

Facility Responsibilities:

Incorporates federal law --- Facility must:

- Provide a private meeting space for the FC.
- Designate a staff person to assist and respond to written requests of the FC.
- Consider the views and act promptly upon the grievances and recommendations of the FC concerning issues of resident care and life in the facility.

Additional federal rights as of September, 2016 --- Facility must:

- Take reasonable, and timely steps, with FC approval, to make family members aware of upcoming meetings.
- Have the designated staff person approved by the FC and the facility.
- Be able to demonstrate their response and rationale for responses to the FC. This should not be construed to mean that the facility must implement as recommended every request of the FC.

Additional MA rights --- Facility must:

- Make private space available at least monthly at mutually agreed upon hours.
- Respond in writing to FC written requests or concerns within 5 business days.
- Not willfully interfere with the formation, maintenance or promotion of a FC. Willful interference includes, but is not limited to, discrimination or retaliation against a FC member.
- Upon admission of a resident, inform designated family members or representatives of a new resident of their right to form a FC, and if a FC exists, notify them about the FC contact and meeting date/location.
- Provide adequate space on a prominent bulletin board or other posting area so that family councils can post family council notices/information (per MA Department of Public Health Circular Letter DHCQ 12-04-447 1/5/05).

Penalties:

Additional MA rights:

- A violation of this law will constitute a violation of resident rights. The Department of Public Health shall impose a civil penalty upon any person who violates this law and shall promulgate such regulations as may be necessary to implement this law.

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 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:

When you and other family members or friends decide to start a family council, request a meeting with the administrator to enlist his/her support and to discuss the date(s) and time of council meetings, where you can post notices, the designated staff liaison, the process for submitting and responding to concerns of the family council. (See Sample Introduction Letter to Administrator – page 8.) You don't need the cooperation of the administrator, but it helps if you want to reach out to new and current family members, and if you really want to see changes rather than resistance. It's always better to start out on a cooperative basis. However, if the administrator will not meet, send a letter of introduction, and then start the family council. By law, the facility is prohibited from interfering with the organization of family councils. A presentation of the idea at a staff meeting would also be helpful, so that all nursing home personnel understand and do not feel threatened by the creation of a family council.

Plan an initial meeting with families and friends:

Invite all families and friends of the residents to a meeting to determine if they are interested in having a council, and, if so, 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 home, because all interested family members and friends may not be included on the home's mailing list. Or

Organize 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 families themselves will run the council, 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. MANHR can provide a speaker and/or informative videos and literature.

The Introductory Meeting (continued):

b) Organizing: Present a plan positively with an attitude that “we can accomplish”. It is important that the principle of self-determination is established by making it the group’s decision to form the council. (See page 10 for sample of by-laws.)

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 keeps the family council from becoming a personal agenda, rather than a group agenda. Also, consider setting term lengths for positions, preferably one year, but no longer than two years if possible. Additionally, the chairperson and other positions should not speak on behalf of the group without its permission.

Staff Involvement:

Members may suggest that the facility 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 was staff-run, interest and attendance steadily declined or the council lapsed into a purely social group. 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 talk in private.

Structure:

Decide on the basic structure of the family council. 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. The steering committee can include all officers, sub-committee chairpersons, representatives of each unit, or elected members.

TIPS FOR AN EFFECTIVE FAMILY COUNCIL

1. Involve Facility Staff:

While at least some part of every meeting should allow for the family council to meet in private, the staff liaison or other staff can be invited for a portion of the meeting to discuss specific concerns. For example, if there is a problem concerning dietary issues, invite the dietician to talk to the council, answer questions and address these concerns.

2. 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. (See Sample Minutes – page 11.) The issues and/or concerns should be agreed upon at the end of the meeting, and there should also be consensus on the format and tone of conveying the message. If you don't put it in writing, don't expect a timely response. Be concise and direct, and give examples of the problem, without naming residents or the connected person citing or involved in the situation. (See Sample Form – page 12.)

3. 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 upset by the time of the first meeting. However, it's a good tactic to lay out all issues and prioritize. Pick one or two less serious issues first to learn how to work with the administrator and to achieve some "wins" for the residents and family council. It's also unrealistic to expect all your concerns to be dealt with at once. Any concerns discussed with administration/others should also be submitted in writing, along with any family council recommendations.

4. Do Your Homework:

Find out the laws and regulations regarding family council issues. If you don't know your rights or the residents' rights, you won't know if the facility response is appropriate. Contact your Ombudsman for assistance, and also use the MANHR website www.manhr.org for links to federal and MA regulations and for information on various issues.

5. Prepare an Agenda:

Although some time needs to be set aside for free discussion of concerns, the meetings should have some structure. (See Sample Agenda – page 11.) 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 date of the next meeting.

Tips For An Effective Family Council (continued):

6. Encourage Productive Meetings:

Develop a process for productive meeting discussions to give all members the opportunity to voice ideas/concerns. Do you want folks to raise their hands to be called on? One idea to give all members a chance to voice ideas/concerns is setting a limit on comments (maybe 2-3 minutes), until all have had a chance to talk. Mention the process at the beginning of each meeting to inform new members and achieve productive discussions.

7. Don't Be Too Formal:

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!

8. Involve the Residents:

Invite any resident who wants to attend. Their voices are the ones that seldom get heard! Family members may also want to bring their loved one to meetings as a way to combine visits with the meeting.

Also, reach out to the Resident Council to collaborate on projects and support their efforts.

9. 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 current and new family members know about the meetings. See Sample Introduction Letter to New Family Council Members – page 9.

You'll need to be innovative to outreach to potential members, and here are some ideas:

- Have a few introductory, short get-togethers on a weekend and at different days/times.
- Ask a few family council members to be “welcoming ambassadors” to greet folks in the lobby (clear with family council liaison first).
- Suggest council members wear pins that read “Ask me about our family council”.

Sample Introduction Letter to the Administrator

Date

Mr./Ms. _____, Administrator
ABC Nursing Home
Address

Dear Mr./Ms. _____:

I am writing on behalf of several family members to let you know that we are in the process of organizing a family council. We hope that through the family council, we will forge a partnership with management and staff that will enhance the quality of care for all residents.

Please let us know which staff person will be designated to provide assistance to the family council and respond to our questions and concerns. I will contact (him/her) to introduce myself and the family council.

Our first meeting is planned for (date) from (time-period), and ongoing meetings will be once a month on the (1st-4th) (day of week), between (time-period). We will ask the liaison to designate a meeting room for the meetings, and we will also ask where we can post meeting notices.

Meetings typically will be limited to families and representatives of residents, with attendance by invitation for the family council liaison, administration, staff and speakers. Of course, there will be many occasions when we hope to meet with you and other managers. One of the purposes of our family council is to promote better communication with management.

The family council will work through the liaison to give you a summary of the questions and concerns discussed at our meetings. We thank you in advance for providing us with written responses within 5 working days to inform us about actions that have been or will be taken on various family council matters.

Please let me know if you have any questions, and we look forward to working with you on behalf of all the residents.

Sincerely,

(Type Name), Family Council Representative

cc: _____, Regional Ombudsman Program Director

Sample Introduction Letter to New Family Council Members

ABC NURSING HOME FAMILY COUNCIL

LETTER OF INTRODUCTION

On behalf of the ABC Nursing Home Family Council, we welcome you as a prospective member of our group. We are a compassionate group of family members and friends of the residents who have joined together to advocate for not only our loved ones, but for all residents in the facility.

Please take the time to read our Mission Statement, Purpose and By-Laws. If you have any questions, contact any one of our Officers.

MISSION STATEMENT

The ABC Nursing Home Family Council is a committed group of families and friends of the residents living in ABC Nursing Home. The Council facilitates communication with management and staff to promote decisions and programs benefiting all residents.

PURPOSE

- ❖ **Improve the quality of care and quality of life of all ABC residents.**
- ❖ **Develop recommendations to advocate for all ABC residents.**
- ❖ **Support each other in the nursing home experience.**
- ❖ **Educate members on long-term care issues.**
- ❖ **Further good working relationships with ABC administration and staff.**

OFFICERS

<u>Title</u>	<u>Name</u>	<u>Telephone #</u>	<u>Email</u>
<u>Chairperson</u>			
<u>Vice-Chair</u>			
<u>Secretary</u>			
<u>Treasurer</u>			

(Include page 10 on back of Introduction Letter)

Sample Bylaws

ABC NURSING HOME FAMILY COUNCIL BYLAWS

MEMBERSHIP

Relatives and friends of residents are welcome to become members of the family council. Family members of deceased residents are encouraged to continue their active membership.

OFFICERS AND COMMITTEES

Family council officers: Chairperson, Vice-Chair, Secretary, and Treasurer.

The Chairperson shall preside over all meetings. In the event of his/her absence, the Vice-Chairperson shall preside over the meeting. The Secretary shall record the minutes of each meeting. The Treasurer shall collect any funds generated by the Council, maintain records on the collection and use of those funds, and submit a report to the Council at least monthly and upon request by the other Officers.

The Officers may set up committees, such as Activities, Welcoming, Education, etc.

ELECTIONS

Elections shall be held once a year in (month).

MEETING DATES/TIME

Fourth Wednesday of every month from 5:00 - 6:30PM [example only].
The Family Council does not meet in December or August.

RULES OF ORDER

Meetings will follow the agenda prepared by the Officers. Each person wishing to speak shall be respectful of the discussion time available for all members. When a person is speaking, courtesy and attention, by all members, should be given to that individual.

Sample Minutes
(Base on Agenda)

ABC NURSING HOME FAMILY COUNCIL
(date) MINUTES

Agenda:

1. Introductions
2. Prior meeting [_(date)_] minutes read and accepted.
3. Announcements: Coffee Hour scheduled for _(date)_
4. Administrator's response to concerns from _(date)_ meeting:
Assistance with feeding: DON has rescheduled staff to assist residents.
Loss of items: Forms for reporting lost items will be mailed to families.
Wednesday AM Art Class: Time changed to 10:30 so more residents can attend.
5. New Business
 - A. Concerns:
 1. Several families reported that pills should be crushed for their relatives, but this isn't done consistently.
 2. Are families' phone numbers up-to-date in office? Request administrator to update by mail.
 - B. Volunteers are requested for New Families Welcoming Committee February event.
 - C. February Family Council meeting speaker will be the Activities Director
 - D. Will try to get speaker from the Dept. of Public Health or Alzheimer's Association for April meeting.

Jane Doe, Acting Secretary

Date: _____

Sample Form to Address Family Council Concerns

**ABC NURSING HOME FAMILY COUNCIL
ISSUES AND RECOMMENDATIONS**

Issues	Family Council Recommendations	Submitted To		Actions Taken By Facility (Include Responsible Parties)		Completed
		Date	Name	Date	Action	Date
Walking program	Engage resident if able, otherwise engage responsible party, to discuss options for program.					
Insure water is easily available to residents	Extra servings of water handed to residents who don't or can't get for themselves.					

Family Council Notice - Example for Admissions Packet

Below is an example of a Family Council Notice to include in the admissions packet in order to comply with Massachusetts Chapter 111, Section 72Z (k):

“When a family council exists during the admission process, the facility shall inform family members or representatives of new residents, who are identified on the admissions agreement, or in the resident’s records, of the existence of a family council. The notice shall include the time, place and date of meeting and the person to contact regarding involvement in the family council.”

Family Council Notice

A resident’s family members (or representatives) have the right to form an independent Family Council, as supported by federal and state regulations (attached). Independent Family Councils, managed by family/friends/representatives of residents, provide members with confidentiality, and an avenue for advocacy and addressing concerns with a facility’s administration.

Family councils are committed to improving the quality of care and quality of life for all residents in a nursing home. In addition to advocacy efforts, Family Council goals also may include supporting members in the long-term care experience, educating members on long-term care issues, supplementing activities programs, and running staff recognition events.

Family Council Information

Family Council Contact:

Phone:

Email:

Meeting Frequency and Time:

Meeting Location:

[Attach this Notice to a copy of the federal and Massachusetts family council regulations (see page 15).]

Federal and Massachusetts Family Council Regulations

Federal Regulations: Title 42, C.F.R., Section 483.10(f)(5)-(7) Participation in resident and family groups.

- (5) The resident has a right to organize and participate in resident groups in the facility.
 - (i) The facility must provide a resident or family group, if one exists, with private space; and take reasonable steps, with the approval of the group, to make residents and family members aware of upcoming meetings in a timely manner.
 - (ii) Staff, visitors, or other guests may attend resident group or family group meetings only at the respective group's invitation.
 - (iii) The facility must provide a designated staff person who is approved by the resident or family group and the facility and who is responsible for providing assistance and responding to written requests that result from group meetings.
 - (iv) The facility must consider the views of a resident or family group and act promptly upon the grievances and recommendations of such groups concerning issues of resident care and life in the facility.
 - (A) The facility must be able to demonstrate their response and rationale for such response.
 - (B) This should not be construed to mean that the facility must implement as recommended every request of the resident or family group.
- (6) The resident has a right to participate in family groups.
- (7) The resident has a right to have family member(s) or other resident representative(s) meet in the facility with the families or resident representative(s) of other residents in the facility.

Massachusetts Regulations: Chapter 111, Section 72Z.

- (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 the mutually agreed upon hours.
- (b) For the purpose of this section "Family council" means a meeting of family members, friends or representatives of 2 or more residents to confer in private without facility staff.
- (c) The facility will inform family members upon the admission of a resident of their right to form a family council. The facility shall not deny a family council the opportunity to accept help from an organization or individual outside of the facility.
- (d) Facility policies on family councils shall in no way limit the rights of residents, family members, and family council members to meet independently with outside persons.
- (e) Intentionally omitted.
- (f) The facility shall not prevent or interfere with the family council receiving outside correspondence which is addressed to the council. Family council mail shall be delivered unopened to the governing body or contact person of the council.
- (g) Staff or visitors may attend family council meetings at the group's invitation.
- (h) The facility shall provide a designated staff person who shall be responsible for providing assistance to the family council, if requested by the council, and responding to written requests that result from family council meetings.
- (i) The facility shall consider the views and act upon the grievances and recommendations of the family council concerning proposed policy and operational decisions affecting residents care and life at the facility.
- (j) The facility shall respond in writing to written requests or concerns of the family council within 5 working days.
- (k) When a family council exists during the admission process, the facility shall inform family members or representatives of new residents, who are identified on the admissions agreement, or in the resident's records, of the existence of a family council. The notice shall include the time, place and date of meeting and the person to contact regarding involvement in the family council.
- (l) No facility shall willfully interfere with the formation, maintenance or promotion of family council. The willful interference with a family council shall include, but not be limited to, discrimination or retaliation in any way against an individual as a result of his/her participation in a family council or the willful scheduling of facility events in conflict with previously scheduled family council meetings.
- (m) A violation of this section will constitute a violation of resident rights. The Department of Public Health shall impose a civil penalty upon any person who violates this section and shall promulgate such regulations as may be necessary to implement this section.

Also, per MA Department of Public Health Circular Letter DHCQ 12-04-447 1/5/05: Nursing homes must provide adequate space on a prominent bulletin board or other posting area so that family councils can post family council notices/information.