

The Family Council Guide

A guide to organizing and maintaining an
effective family council

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Office of Long Term Care

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INTRODUCTION

The Family Council Guide is written to assist family members and/or nursing homes in the state that desire to organize a new family council or to re-organize an existing one. (For more information about family councils, contact the Office of Long Term Care). It is designed to assist family groups and/or nursing homes of different sizes as well as those that have special needs. For the small nursing home with a few active families, it gives some brief, concrete ideas on how to organize and manage an effective council. Also, for those small councils that may have experienced less success and that consider re-organizing, the manual provides insight and positive steps to follow in reorganization so success can be achieved.

In larger nursing homes where there has been difficulty getting the council organized but where interest is present, the manual can give very definite, simple steps to follow if re-organization is desired. It will also give insight and understanding into the needed ingredients for building and maintaining an active, successful council.

CHAPTER ONE

Where to Start

The purpose of the family council is to protect and improve the quality of life for the residents in the home and to give families a voice in the decisions that affect them and their loved ones. **The federal regulation 42 C.F.R. § 483.15 explains the role of the family council:**

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.

(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 operational decisions affecting resident care and life in the facility.

Many family councils are initially started by nursing home staff, often at the administrator's request. Some, however, are started by interested families, friends, a volunteer, or community leader. How a family council is organized can determine its effectiveness, success, or failure. Here are some factors that need to be considered:

1. Family interest for a council;
2. Introducing families (individuals) to the idea; and,
3. Encouraging families to participate.

First, talk individually with a few of the more involved family members. Seek out those that are more positive minded and open to new ideas and those who have already been involved in constructive endeavors around the nursing home. You must, however, be convinced of the value of having a council yourself before you can talk with anyone else about it. Also, it is essential to discuss the idea with various staff members who can be very helpful with ideas and suggestions. Such discussion would lessen the possibility of the staff feeling threatened by such a group.

If the administrator and staff are attempting to start the council, it would be best to start by meeting with a small number of families already familiar with the nursing home. A staff person could begin the meeting and then relinquish control to an appointed family member. It is important to allow the families to run the meeting even though it may be somewhat time-consuming in the beginning.

The most important method of starting a council is to hold a meeting to which all families of residents are invited. The purposes of the meeting are to:

1. Explain the concept of family councils;
2. Determine their interest in having one; and,
3. Begin organizing one, if interest is present.

The success of the first meeting is largely dependent on personal contacts with key family members, the number of families who were contacted, and how attractive you can make the meeting sound. The introductory meeting, however, has a great deal to do with the success or failure of an attempt to organize a council. Below are listed some of the components the introductory meeting should have:

1. An explanation of family councils;
2. Discussion;
3. Decision on the desire for a council;
4. Plans for the next meeting;
5. Selection of temporary officers;
6. Decision on the structure of the meeting; and,
7. Decision on staff advisor, who it will be and whether he/she will attend all meetings, or parts of meetings.

Start the meeting with a warm welcome and express appreciation for their coming. Next discuss the purposes, importance, and structure of family councils. Avoid the appearance that this group is just another social group, or that the nursing home seems to be starting it for its own purposes. Also, allow adequate time for family members to ask questions and discuss their ideas about a council. Never assume that families want a council. Make sure that they express the desire to have one and take ownership in its development.

Some important items to consider in the first meeting are meeting time, date, place, topic, and selection of temporary officers. The meeting time and date should be selected to accommodate

families, not set at the convenience of staff. Many councils find weekends to be a good time to meet, since families and friends are already visiting the nursing home.

The meeting place needs to be one where families can feel relaxed and free to express themselves and ensures privacy without interruption from others. The facility is required to provide a meeting room if the group wishes to meet at the nursing home. Other possible good locations include: libraries, local churches, community centers, senior centers and banks. Seek to avoid large rooms that make it difficult for families to be relaxed and speak openly.

The topic for the next meeting should be chosen by family members. Often, families will decide to spend the next meeting discussing their problems and concerns and/or deciding on the purposes of the council.

The next item of concern is the selection of temporary officers. Councils usually begin with temporary officers who serve until regular elections are held. It is possible that those who were involved in planning the introductory meeting may be willing to lead temporarily.

Staff advisors should never agree to become an officer, because it will be much harder to convince families to take responsibility for the council later. Establish clearly in the beginning the principle that the council is run by and for families.

Next decide on the basic structure of the council. If the group is small, the council usually invites all families to each meeting. However, if the group is large, committees may be needed to plan and make decisions.

Next the council should decide if they want a staff advisor. Even in the best of nursing homes family members may feel some reluctance in expressing concerns in front of staff. Two possible solutions to this are: 1) encourage council members to meet in private occasionally, or 2) spend a portion of each meeting without staff present.

The group needs to make a decision concerning the attendance of residents. Residents' needs are served by a resident council. Be aware that free expression by family members may be hampered by residents' attendance at meetings.

CHAPTER TWO

Planning Family Council Meetings

A major factor in a meeting's effectiveness is advanced planning. Equally as important as the planning of activities and projects is the importance of planning meetings. If the council is experiencing problems of any sort relative to the meeting, inadequate planning could be the cause.

During a meeting of the executive committee or the council, make a list of anything that has gone wrong or created confusion during recent meetings. Then, discuss which problems might have been avoided by more thorough planning. Especially examine problems that arise repeatedly. Then, discuss how future meetings can be planned so that these and similar problems can be minimized.

A meeting checklist can be most beneficial. It is simply a "reminder" of the tasks that need to be done to arrange a meeting. Below are some items that should be included in a checklist with a few examples of things that should be included under each one:

Locate and Reserve the Meeting Room

- ◆ Discuss the amount of meeting space needed.
- ◆ Choose space that meets the needs of the group.
- ◆ Arrange the needed equipment.

Planning the Agenda

- ◆ Decide on meeting topics and format.
- ◆ Identify issues that need discussion.
- ◆ Assign meeting responsibilities to council members.

Notifying Participants

- ◆ Internal sources; i.e., newsletters, calls, mailed notices.
- ◆ Public sources; i.e., mail, radio newspapers, bulletin boards (See page 17 for example of notice to families).

Gathering Resources

- ◆ Contact speaker or others who have roles in the meeting and provide any information they might need.

- ◆ Secure needed written materials and prepare any copies needed for the meeting.
- ◆ Arrange for audio/visual materials and equipment needed.

Tasks to Do at the Meeting

- ◆ Arrange refreshments, water for speakers, etc.
- ◆ Distribute agenda or other handouts.
- ◆ Welcome new members.

Tasks for After the Meeting

- ◆ Send thank-you notes to appropriate persons; i.e., speakers, meeting hosts, etc.
- ◆ Follow-up discussions/decisions with any necessary letters and phone calls.
- ◆ Prepare and distribute minutes.
- ◆ Begin planning for the next meeting.

CHAPTER THREE

Processing Family Council Concerns

In their effort to protect and improve the quality of life of residents in the home, the group of family members known as the family council has the privilege and responsibility to hear and act on concerns that family members have.

Processing concerns in a group can be effective for several reasons. An individual who has a question or consideration may find through sharing their concern in a group that several others have the same burden. The concerns of several people usually receive a quicker response followed by some positive action to address the matter. Also, the time and energy required to address a matter or problem can be shared by the group rather than by individuals separately.

Hearing and processing family members' concerns is one of the most important functions of the family council. However, much care must be taken to ensure that this doesn't become the only function and the one to which most of the meeting time is devoted. Placement of a family member into a nursing facility is stressful for both the resident and the family. Concerns will arise in reference to care issues and expectations. The family council is a supportive environment in which to discuss these.

Sometimes problems are unavoidable in any nursing home. The family council offers the administrator and facility staff an opportunity to:

1. Address small issues before they become major problems.
2. Hear constructive input from families.
3. Keep families informed of changes and issues affecting the nursing home.
4. Seek family support on issues affecting both family and family members.

Each of the above is very important, but of utmost importance is developing a cooperative, honest relationship that will be ongoing. It is hoped that when the family council brings concerns to the attention of the nursing home, they can work together to bring about resolution that will best serve the residents.

Providing the Opportunity

Examine your council's meetings. Is the council really encouraging open discussion of members' concerns? Do family members feel free to express their concerns? Or is the meeting dominated by "complainers"? Is resident or staff presence hindering discussion? The purpose of the council is not only to voice concerns, but also to work toward meaningful change - to find solutions to problems.

Processing a Concern in the Group

The effectiveness with which the council processes problems or concerns is an important indication of the degree of success the group enjoys. Below are listed some ideas that can be used to bring about that success.

1. Allow the member to fully explain his/her concern.
2. Determine if other members share the concern.
3. If members feel there is an issue they wish to pursue, they will have to determine if:
 - a. They have the information and time to do it at the meeting; or,
 - b. They wish to wait till a future meeting to pursue the matter.
4. In some cases, additional information may need to be provided by the administrator or other staff person who might be invited to speak to the group. Also, an outside speaker might be called in to offer needed insight and information on a topic. Make sure you understand all applicable regulations and requirements.
5. Seek creative suggestions from council members for problems and concerns.
6. Formally present your concerns and ideas to the facility staff and administrator.
7. Allow adequate time for replies and facility action. Refrain from unreasonable demands.
8. If the facility fails to cooperate and ignores the council's concerns, proceed with further action. (See next sections)

******* Expressing Your Concerns *******

Some ways of expressing concerns are more effective than others. The following guidelines will hopefully provide you with good information that will enable you to make effective suggestions for change.

1. Begin first by determining the facility's policy and applicable regulations for the area of concern. Time and effort can be saved if there is a good understanding of these guidelines and how they impact the care of residents.
2. Take concerns to persons who are responsible and have the knowledge to help.
3. Make an appointment in advance, unless an emergency exists.
4. Have the details of your concern written down in advance and take them with you.

5. State your case in a friendly, but firm manner. Refrain from angry outbursts and assume the concern will be dealt with effectively.
6. Avoid generalities; i.e., "inadequate care," "bad meals," and exaggerations; i.e., "it always happens..." or "everyone's personal items..." Instead, be prepared to give specific examples of the problem or concern.
7. Allow reasonable time for resolution of the concern. Ask when you may expect a response.
8. Show appreciation when things go well.

Processing Concerns Beyond the Nursing Home

Most concerns can be discussed and resolved without going beyond the nursing home. However, there are three general areas where the complaint may need to be resolved by other means.

1. Emergencies - An emergency is any situation in which the resident's health and safety is endangered; or where the resident is suffering abuse or unnecessary pain. Normal complaint procedures would take too long. If, in your opinion, a resident is in danger or is being abused, report it to the staff immediately.

If the problem is not resolved, or you feel it should be reported further, go to the administrator. If you cannot go to the administrator, if the problem is still unresolved, or if it is so severe you feel it should be reported beyond the nursing home, call an agency empowered to protect the residents.

2. If there is difficulty with the nursing home responding to a concern, seek to involve the Ombudsman.
3. If concerns are not resolved by facility staff - First, find out if the concern involves any violation of the regulations that govern long term care. Review applicable laws and regulations. Also, look at the Residents' Rights. If you are still unsure, contact your local or regional Ombudsman.

In Arkansas, complaints are accepted at the State Office of Long Term Care. Also, if there is suspected abuse, the same office should be called. **THE NUMBER IS: 682-8425** for Pulaski County residents. For those outside of Pulaski County, you can call toll free at 1-800-582-4887.

CHAPTER FOUR

Possible Council Activities

Projects to Strengthen Relationships Between Administration, Staff, Residents, and the Council

- ◆ Submit suggestions for policy changes
- ◆ Special recognition to staff for commitment and service
- ◆ Cooperation on joint projects with the resident council
- ◆ Sponsorship of activities and events enjoyable to both residents and families

Projects to Stimulate Interest in the Family Council

- ◆ Publish a family council newsletter or contribute a column to the existing facility newsletter
- ◆ Establish a family council bulletin board to be maintained by council members
- ◆ Conduct "get acquainted" meetings for families
- ◆ Orientation for Families of New Residents

All family council members have at one time been newcomers to the world of long-term health care. Council members have experienced the difficulties of having a loved one move into a nursing home. Many councils have some form of welcome and orientation for new families. This can be rewarding, and is also an easy project for a council (even a new or small council) to carry out.

The type of orientation chosen by a council will have much to do with the size of the council, how frequently new residents are admitted, and what seems more natural or comfortable for the council. Another consideration is the amount of cooperation from the nursing home.

In some nursing homes, information on the family council is given when a new resident is admitted to the nursing home. (See the last page of this guide for an example orientation letter) One real advantage is that a family is offered immediate information and support at this very trying time. Some councils have found their administrator willing to include the letter with other information given to new residents and their families.

Some nursing homes provide periodic orientation programs for new families. Often family councils are part of these programs. In other nursing homes, where facility orientation programs do not exist, councils hold their own. Frequency of such programs depends on the number of new residents coming to the nursing home.

There are several advantages to orientation programs. They offer new families the opportunity to meet other families and to gain needed information and support. A good orientation program will also offer time to socialize, a chance to ask questions, and a speaker or film designed to inform and inspire newcomers. This is an excellent opportunity to tell new families about the family council, its activities, and what it can offer.

Many family councils around the country have welcoming committees that write or call new families, and introduce themselves and the council. They answer questions, offer support, and invite new families to council meetings. This effort helps establish good, positive groundwork for building healthy relationships.

A letter is especially effective when followed by a phone call. New families will be less hesitant to come to a meeting if they feel they already have a friend to welcome them.

Before starting such a project, first determine if council members are really interested. Secondly, if they are interested, determine what type of orientation project they want to undertake. Things such as members' time, skills, and interests must be considered.

The council will want to be involved in other activities and it should be cautious not to take on more than it can accomplish. Talking with other councils who are involved in a similar type of orientation project can help members make a wise decision.

After the council determines what it wants to do, it should then consult with the administrator. Working closely with him/her will more likely ensure the success of any project. Here are some important points to discuss with the administrator about the value of family orientation:

1. Informed families will have fewer questions and concerns to direct to busy staff.
2. By encouraging new families to participate in a council, the facility is demonstrating a sincere concern for family welfare and quality of life within the nursing home. It also shows an openness to work with family members and a desire to be of assistance.
3. A family orientation system is likely to reduce turnover in the nursing home's resident population by reducing dissatisfaction and frustration among families.

Project Ideas to Meet Resident Needs:

- ◆ Organize a visitation program for residents with few or no visitors
- ◆ Establish and operate a gift shop or shopping cart to sell small items room to room
- ◆ Provide transportation to activities, both inside and outside facility
- ◆ Establish a fund for residents with special personal or activity needs, i.e., haircuts, special shoes, etc.

Projects for Resident Activities and Programs

- ◆ Special entertainment programs; i.e., choral groups, a play, classical or country western music, etc.
- ◆ Holiday parties
- ◆ Summer picnics and cookouts
- ◆ Pancake feasts, ice cream parties - opportunities to provide some foods residents are not often served
- ◆ Outings; i.e., shopping, cultural events, zoo trips, etc.
- ◆ Gardening in raised containers, within wheelchair reach

Projects Benefiting Families

- ◆ Parties or events welcoming a new family member
- ◆ Complete a family guide about the nursing home
- ◆ Creation of a lending library of books and pamphlets relative to aging, specific health problems, etc.
- ◆ Sponsorship of a family support group
- ◆ Visiting speakers program

Possible Speakers

- ◆ Medical Director
- ◆ Attorney General
- ◆ Governor's Office
- ◆ Ombudsman
- ◆ Office of Chief Council
- ◆ University of Medical Services
- ◆ Support Groups (Alzheimer's Disease, etc.)

- ◆ Office of Long Term Care

Projects Involving Fund-raising or Donations

- ◆ Stereo equipment for music during meals
- ◆ Microwave for warming meals or snacks
- ◆ Bulletin boards or other displays to show pictures of residents, activities, or special events
- ◆ Potted plants for rooms and public areas
- ◆ A vegetable or flower garden
- ◆ A patio, gazebo, or other area that residents can enjoy

Fund-Raising Ideas

It is not possible to list all the fund-raising projects that have been used successfully by family councils. However, some that have been frequently used are listed below:

- ◆ Food sales
- ◆ Rummage sales
- ◆ Bazaars
- ◆ Running a shop in the nursing home
- ◆ Raffle a quilt made by council members
- ◆ Host an art fair open to the community
- ◆ Hold a used book sale
- ◆ Collect cans or newspapers for recycling

Council Projects

Family council projects can be an effective means of involving family members in the life of the nursing home. At the same time, it allows council members to make a valuable contribution to the residents and the nursing home. Also, if planned and implemented wisely, projects can result in positive change. Here are some suggestions for choosing and planning a project that should provide great help:

- ◆ Define the purposes and goals of the project.
- ◆ Learn about the interests and concerns of members.
- ◆ Be sure to contact the resident council prior to planning a project to benefit or involve residents.
- ◆ Discuss the tasks that need to be done prior to choosing the project.
- ◆ Appoint a committee to coordinate the project.
- ◆ Establish a plan for accomplishing the project with specific deadlines.
- ◆ Include as many family members as possible.
- ◆ Advertise the project before and after its completion.
- ◆ Make the project as enjoyable as possible.
- ◆ Take time to evaluate the project when it is completed.
- ◆ Acknowledge the efforts of all involved.

Planning the Project

After the council has chosen a project, a realistic work plan should be developed. Each task to be accomplished should be listed. Take time to share plans with residents if they will be affected. Talk with the resident council for their input as well.

An important aspect of planning is choosing a date and time that does not conflict with other activities or events. Make sure there are no other activities on that day. Check with the Chamber of Commerce and other groups in the community to learn if there are other events already scheduled.

Enlist the help of as many council members and family members as possible. Letting people know they are needed and important to the success of a project is very important for many reasons. Occasionally fund raising may be desired to support other projects. Finally, there can hardly be enough publicity for a project, especially where community support is needed.

Whatever project is selected, remember that need, interest, involvement, and planning are essential to its success. Take time to evaluate the success or difficulties of the project before beginning another.

Conclusion

The membership of a Family Council will undergo changes along with the population changes in the facility. It will be important to establish a good record-keeping system so that the past efforts of the group can be reviewed. Their experiences can be invaluable in determining the direction of the group and deciding on future endeavors.

Each family council will be diverse depending on the needs of the residents and their families. Larger nursing homes may have larger and more organized councils while others may be smaller and more unstructured. It is hoped that this guide will be helpful as you establish your group. Our staff will be happy to assist you as you determine the direction and needs of your council. Good luck in your endeavors.

NOTICE

TO

FAMILIES

For information about the _____
(name of nursing home)

Family Council, please call _____ or see
(telephone number)

_____. The
(name)

Family Council meets every _____
(list date; i.e., third Thursday of the month)

at _____ in _____ .
(time) (location)

President

Example of Orientation Letter for Families of New Residents

A warm welcome to you from the Family Council of _____. Our group has a primary goal of protecting and improving the quality of life for our family members. We know it is difficult to have a loved one move into a nursing facility and the feelings of guilt, isolation, bewilderment and loss can be overwhelming. We have all shared this same experience and can provide a special support to one another.

We encourage your participation as we discuss concerns and issues as well as plan future projects. Our group meets _____ at the _____. If you have questions or concerns, please call _____ or _____ and they will be happy to visit with you. We hope to see you at our next meeting!