

FAMILY GUIDE TO EFFECTIVE FAMILY COUNCILS

**Prepared for:
The Legal Assistance Foundation
of Metropolitan Chicago
and the
Evanston Commission on Aging**

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National Long-Term Care Ombudsman Resource Center
National Citizens' Coalition for Nursing Home Reform
www.ltcombudsman.org

202-332-2275

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***NEVER DOUBT THAT A SMALL GROUP OF THOUGHTFUL
COMMITTED CITIZENS CAN CHANGE THE WORLD; INDEED IT'S
THE ONLY THING THAT EVER DOES.***

Margaret Mead

INTRODUCTION

Far too often people think that there is nothing they can do to improve a situation or make a change. They say, "What can I do? I'm just one person." Well, as the quote cited above illustrates, that one person can join with another, and then another. What one person may not be able to accomplish, a group can.

When people come together and speak with a united voice, positive change can happen. Not only can they achieve concrete results, they can experience the benefits of developing closer relationships with each other and a stronger sense of community.

A nursing home family council that is run by family members can be a powerful force for improvement in a nursing home. Many councils across the country have been able to increase the quality of life and well-being of their loved ones through their work.

This guide is designed to help families develop and maintain a strong, effective, family-run family council. It provides step-by-step guidance, as well as sample forms that can be used. But, councils - like people - are unique, and so the suggestions presented in this book should be adapted to fit the needs of *your* council.

CHAPTER ONE

AN OVERVIEW OF FAMILY COUNCILS

I. WHAT IS A FAMILY COUNCIL?

A family council is a self-led, self-determining group of consumers - families and friends of nursing home residents - that:

- Works to improve the quality of care and quality of life of the facility's residents; and
- Provides families with a voice in decision-making that affects them and their loved ones.

Many voices are stronger than one. The power of a lot of people working together is enough to make changes, whereas one person can often do very little.

Family councils can:

- Act on concerns and complaints affecting nursing home residents;
- Support families;
- Communicate with the nursing home administrator and staff;
- Serve as a sounding board and advisory body on new ideas and improvements;
- Advocate for positive change within the facility and the long term care system;
- Educate and inform families about issues relating to residents, the nursing home and the long term care system; and
- Sponsor activities that benefit all residents.

A family council is **not**:

- A support group
- A family night
- A volunteer group

While these other groups perform a very important function, their role is different from that of a council.

II. PHILOSOPHY OF A FAMILY COUNCIL.

Family councils strive to work in partnership with the nursing home administration and staff to solve problems and ensure that residents receive the best possible care. While this may not always be possible, it should certainly be the goal. Councils and facilities that work together can accomplish much more than those that are at loggerheads.

III. IMPORTANCE OF A FAMILY-RUN FAMILY COUNCIL.

Experience has shown that councils that are run by families, and not staff, are more effective for several reasons:

- Members are more likely to feel responsible for the success or failure of their council. There is a sense of direct ownership in the work of the council.
- Family member interest is stronger because families determine the issues and activities that the council takes on.
- Staff members have many other responsibilities and simply cannot devote the necessary time to do all that needs to be done to run an effective council.

IV. BENEFITS OF A FAMILY COUNCIL.

A. For Nursing Home Staff.

- Provides the administration and staff with information about concerns that families have about resident care so that problems can be responded to in an appropriate manner.
- Gives the facility the opportunity to find out about and fix problems in the facility rather than having families turn to outside agencies such as the survey agency or the ombudsman program for help.
- Can provide creative solutions to problems.
- Gives honest feedback to use for ongoing quality improvement efforts.
- Provides an avenue for requests for changes within the facility to be made to boards and management companies. Family councils can advocate with these entities for changes that staff may want, but for which they are unable to obtain approval.
- Keeps facility staff from being overwhelmed by a barrage of individual complaints all at once.
- Provides recommendations for programming or policies that would benefit residents.
- Increases the likelihood that new facility policies will be implemented smoothly and successfully and positively impact residents because families will have had an opportunity to comment on and shape these policies.
- Can identify outside resources to enhance the lives of residents and facility functioning.
- Increases family willingness to contribute time and energy towards making the facility a good place for people to live.
- Results in better care for residents!!

B. For Family Members.

- Provides support, encouragement.
- Provides information.
- Gives families a place to constructively channel their concerns.
- Reduces sense of isolation, helplessness, frustration.

- Gives families an opportunity to shape facility policies and procedures affecting their loved ones.
- Improves the care of their loved ones.

C. For Both Families and Facilities.

- Promotes open lines of communication
- Builds a trusting relationship
- Provides the opportunity to make improvements for all residents

D. For Residents (Most Important of All!).

- **Improves their quality of life and quality of care!!!!**

V. RIGHTS OF FAMILY COUNCILS.

Federal law and regulations provide families with powerful rights relating to family councils. These regulations apply to all nursing homes in Illinois that receive Medicare and/or Medicaid funds (“certified” facilities). The regulations state that:

- A resident’s family has the right to meet in the facility with the families of other residents in the facility.
- The facility must provide a family group, if one exists, with private space.
- Staff or visitors may attend meetings at the group’s invitation.
- The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings.
- When a 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.

CHAPTER 2 STARTING A NEW COUNCIL

PHASE 1: FROM THE DECISION TO START A COUNCIL TO THE FIRST COUNCIL MEETING

I. TAKING THE FIRST STEP.

So what do you do if you are interested in forming a family council? Where do you begin?

A. Connect With Other Families.

1. A single family member is enough to start the process!! Begin by talking with other family members you know in the nursing home whom you think may also be interested. See if you can find at least 2 other family members to join with you. (We will call this group **the steering committee**.) While one person can serve as a catalyst, it takes more than one to move forward!
2. Share this manual with the families who have become part of the steering committee so they will know what a council does and how one can be formed.

B. Contact The Local Long Term Care Ombudsman.

The ombudsman is an advocate for nursing home residents and their families. The ombudsman can provide you with direct assistance, training, guidance and support to help you in developing a council.

C. Connect With Family Councils In Other Facilities.

Talk with other family councils to learn how they started. The ombudsman can give you information about facilities that have active councils.

D. Meet With The President Of The Resident Council.

Discuss the formation of a family council with the leadership of the resident council (if there is one). Explain the purpose of the council and its goal of improving quality of life for residents. Point out that you want to supplement, not supplant, the resident council.

E. Meet With The Nursing Home Administrator.

1. The steering committee should plan the approach it will use to talk with the nursing home administrator about forming a family council.

The committee can ask the ombudsman to assist in the planning process.

Think through:

- a. How to present the idea in a positive and enthusiastic way. Point out the benefits to the facility, the residents and the families. See Chapter 1, Section IV.
- b. Anticipate some of the concerns the administrator might have and how you would address those concerns.

Some of the issues administrators may raise and possible responses to those points are presented in the following table.

CONCERN/OBJECTION	POSSIBLE RESPONSE
Administrators may argue the need to have a staff member present to facilitate group interaction and to limit the amount or type of complaints raised by family members.	<ul style="list-style-type: none"> • Many family members are already skilled at group facilitation and those who are not will receive training. • Hearing complaints is helpful to the administrator because it lets him or her know what families think so that problems can be responded to in an appropriate manner. • Federal regulations give families the right to meet privately.
Administrators may encourage family members to join established support groups that focus on adjustment issues and that are staff-led.	<ul style="list-style-type: none"> • The purpose and role of a support group is different from that of a family council. A support group is staff-led and helps members discuss feelings, needs and concerns. A family council is family-led and works to find positive solutions to problems and concerns relating to resident care.
Administrators may state the need for staff to be present as a condition of the group meeting at the facility.	<ul style="list-style-type: none"> • In order for the facility to benefit from what a family council has to offer, families need to have time to themselves. • Federal law allows staff to be present only if invited.
Administrators may state that there is no	➤ Family councils can improve care for

<p>need for a council because families already feel free to voice their concerns and have access to staff at any time.</p>	<p>all residents, even those who don't have any family.</p> <ul style="list-style-type: none"> • Family councils do more than just allow families to voice concerns. They can: <ul style="list-style-type: none"> - Advocate with boards and management companies to request changes that staff (and even the administrator) want, but are unable to obtain approval for; - Provide recommendations for programming or policies that would benefit residents; and - Identify outside resources to enhance the lives of residents and facility functioning.
<p>Administrators may argue that their staff are too busy to concentrate on a family council.</p>	<ul style="list-style-type: none"> • The role of facility staff is not to run the council, but to give families the tools <i>they</i> need to do so. • The ombudsman will be available to support and assist the council and to provide training. This will ease the burden on staff.
<p>Administrators may cite opposition to family councils due to previous experiences in which families raised issues that were confrontational or embarrassing to staff.</p>	<ul style="list-style-type: none"> • Hearing complaints is helpful to the administrator because it lets him or her know what families think so that problems can be responded to in an appropriate manner. • It's better to know what families are concerned about (even if it is confrontational or embarrassing) so that the problem can be addressed. You can't solve problems that have not been voiced.

c. Develop an agenda for the meeting. A sample agenda is found on the next page.

- Greetings/introductions.
- Discussion of reasons for forming a family council/benefits of a family council.
- Discussion of type of council to be formed: an independent self-run council.
 - Note:** It is important to be clear from the beginning that you are talking about a council that is not run by the facility.
- The type of assistance and support the council would need from the facility in order to be successful:
 - Commitment to listen to family concerns
 - Commitment to act on concerns
 - Private space
 - Staff liaison
 - Assistance in publicity and outreach
- Request for the administrator to join with you in developing the council. (If the administrator is hesitant, take time to explore his/her concerns. Clear up any misunderstandings that he or she may have about a council.)
- Request for the administrator to designate a staff person to serve as staff liaison. One role of the liaison would be to work with the steering committee to launch the council.

- d. Set up a meeting time with the administrator. Administrators are very busy, so be respectful of their time by scheduling a meeting in advance rather than dropping by his or her office.
- e. Ask the ombudsman to attend the meeting with you if you feel his/her support and influence would be important. This may be a good idea if you sense that you might encounter resistance from the administrator.

E. Facility Resistance To A Family Council.

If the administrator is resistant to the formation of a council, you can try a number of different approaches:

1. Ask the administrator to help you better understand his or her position so you can know exactly what the concerns are. Find out what ideas he or she has about a family council. In some cases, you may discover that there is a misunderstanding about what a council does, and you can provide additional information to clarify the council's role. For example, the administrator may fear that the council's purpose is to take problems directly to the media. You can stress that the purpose of a council is to work **with** the home for improvements and to promote open communications within the facility.

If you are not getting anywhere at this initial meeting, keep the door open and ask to meet again to continue the discussion. Try to maintain a dialog to chip away at resistance over time. Keep at it.

2. State that what you are hearing the administrator say is that he or she will not support the development of a family council. Ask if you have heard him/her correctly because you want to be sure that you understand and that there are no misunderstandings. If the administrator equivocates and won't be clear, let him/her know that you can only conclude that the facility is not permitting a council to form. Then send a letter to the administrator after this discussion summarizing his/her position. You could also send a copy to the administrator's own supervisor or the facility's board of directors and/or the Department of Health. This might cause the administrator to change his/her position.
3. If you met with the administrator without the ombudsman, seek ombudsman assistance. The ombudsman can go with you to meet a second time with the administrator.
4. File a complaint with the Department of Health about the facility's violation of the family's right to form a family council. Include a copy of the letter discussed in point #2 and the names and contact information of family members for the complaint investigators to interview.
5. Circulate a petition calling for the creation of a family-run council and get as many family members to sign as possible. Send it to the administrator and the board of directors or facility owners.
6. Seek community support.
 - a. See if key players in the community such as referral sources, social service agencies or city officials will meet with the administrator or at least send a letter. If the facility is religiously affiliated, enlist the help of a minister, pastor, rabbi, etc. Keep the pressure on.
 - b. Have community members sign a petition calling for the formation of a council.
7. Write a letter to the editor of your local newspaper or talk with a reporter.
8. Protest in front of the nursing home.
9. Seek the support of your elected officials.
10. Back off for the time being and try again later.
11. Form the council anyway, but hold meetings outside the nursing home.

II. HOLDING AN INTRODUCTORY MEETING

The most important method of starting a council is to hold a meeting to which all families of residents are invited. This introductory meeting can have a major impact on the success or failure of council organization.

The purpose of the introductory meeting is to:

- Determine family interest in a council;
- Obtain family commitment to forming a council; and
- Lay groundwork for the first council meeting.

The steering committee, along with any other interested family members and the ombudsman (if families wish) should meet to plan this meeting.

A. Planning The Meeting.

Planning should address the following points:

1. Meeting place. The location needs to be one where families can feel relaxed and free to express themselves, and where there is privacy without interruption from others. The facility is required under federal law to provide a private space if the group wishes to meet at the home. However, if the facility is resistant, and you can not ensure privacy or family members express discomfort at meeting in the facility, plan to meet outside the home. Possible locations include: libraries, churches, community centers, and senior centers. Try to find a room that is conducive to speaking openly and that puts families at ease.
2. Date and time. Select a time when you think most families would be able to attend the meeting. This will most likely be in the evening or on the weekend.
3. Outreach/publicity. It is very important that **all** families of residents be invited to the introductory meeting!

Ideas for publicizing the upcoming meeting are presented below:

- a. Draft a flier inviting families to the meeting and send it to all family members. See Appendix 1 for a sample flier.

Ways to send out the letter/flier:

- Ask the facility for a list of family members and send the flier yourselves. Ask the facility to cover the cost of copying and mailing.
- Provide the flier to the nursing home and ask that the nursing home send it out. It would be best if the facility did a separate mailing for this flier, but if this is not possible, ask that the flier be included in a billing notice or other facility correspondence.

- b. Seek out other family members and personally invite them to the meeting. Give them the flier. Ask them to invite at least 3 other people. Make a point of reaching out to family members you have not talked with before.

Note: Doing this on a weekend when a lot of families visit can be particularly productive!

- c. Call any family members you know.
- d. Post the flier around the facility and on the doors leading into the home (ask the facility for permission to do so before posting).
- e. Request that an announcement be placed in the facility newsletter.
- f. Ask the staff liaison to talk with as many family members as possible.
- g. Ask the nursing home to encourage all staff to invite families to the meeting.

Obviously, if the facility is not supportive, several of the ideas identified above will not be possible. However, steering committee members can still personally invite family members they meet in the nursing home and distribute fliers. In addition, you can try:

- Placing fliers under window wipers on visitor cars in the facility parking lot.
 - Talking with families in the parking lot.
 - Running an announcement in a local newspaper.
4. Refreshments. Food always helps to attract people! However, it does not have to be anything expensive or complicated. Something as simple as coffee and cookies is fine!
 5. Develop the agenda and plan in advance who will be responsible for covering each point. A sample agenda follows, along with some additional suggestions.

Note: the ombudsman is listed in several places on the agenda. However, steering committee members may be able and wish to cover these agenda items themselves.

INTRODUCTORY MEETING SAMPLE AGENDA

- Welcome/introductory remarks
Reminder to sign in Member of Steering Committee

- Welcome and statement of support
from nursing home Administrator and/or
Department Heads

Comment: The steering committee should decide in advance whether to ask the administrator and staff to leave after their welcome.

- An Overview of Family Councils Ombudsman
 - What is a family council
 - Benefits
 - Rights to form a family council
 - Success stories
 - Discussion/questions

- Discussion/vote on whether to proceed
with formation of a council Member of Steering Committee

- Selection of leadership committee Ombudsman

Comment: The group should select who will lead the council until it is ready for its first elections. The members of the steering committee may be the perfect ones to take this on, since they have already showed a willingness to get involved. However, there may be others willing to step up to the plate!

- Discussion of type of temporary
leadership structure Ombudsman

Comment: The group should determine how it wants to be lead until its first election. It is helpful to have at least 3 people in leadership positions. These could be:

- President (could also be called chair or coordinator);
- Vice-president (could also be called vice chair or assistant coordinator); and
- Secretary.

A treasurer may not be necessary at this point, but will be if the group wishes to do fundraising or have an account that is independent from the facility.

Comment: It may be intimidating to people to be “president.” If this is the case, two people could serve as “co-presidents” or a team approach can be used. For more information about council leadership and structure, see Chapter 3, I. A.

The more people who volunteer, the less each person will have to do!

- Plans for the first meeting of the council Member of Steering Committee or Ombudsman

- Meeting date and time.

Comment: Try to establish a day of the month and time that will work for the most number of people from month to month. Knowing that the council meeting is every 3rd Wednesday at 7:00 p.m. promotes participation.

- Location.

Comment: This should be a place where there is privacy. If the nursing home is resistant or does not have an appropriate room, find a room in the community.

- Topic.

Comment: Determine what the council should address at the next meeting. It is a good idea to focus as soon as possible on:

- identification of areas of interest or concern and action steps;
- identification of mission/purpose of council; and
- organization and structure of meetings and council work.

Find out what members are most interested in and begin with those items. It can help to start with the purposes and goals and bylaws, but the group should decide.

Ask for volunteers to help plan the first council meeting and to assist with publicity and refreshments.

- Discuss staff attendance and ombudsman attendance Member of Steering Committee

Comment:

Staff: The group will need to decide if it wants the staff liaison present during the meeting, or only for part of the meeting. Some families are inhibited when a staff member attends and will not speak out as freely. Others don't care. A compromise position is to have the staff liaison present for a particular part of the meeting only.

Remember: It is the families' decision, not the facility's decision, when, or even if, staff will attend the meeting.

Ombudsman: The group should decide if it wants the ombudsman at the

meeting and what role the ombudsman should play.

- Discuss family issues/concerns Member of Steering Committee or Ombudsman

Comment: If nursing home staff are present when this agenda item comes up, the steering committee needs to decide whether they want staff to leave. It is probably a good idea to have this part of the meeting be for family members only because:

- Many family members will not speak up if staff are present.
- Families may need to vent their frustration and anger before turning to problem-solving, and it is not productive for nursing home staff to hear this.
- It may take a period of time before the problems can be carefully defined and discussed with staff.

Comment: Focus on concerns that are facility-wide and resident-centered. As a group, prioritize the concerns and select one to address first. Ask families to come to the next meeting with ideas about possible solutions.

Comment: See Chapter 6 for ideas about prioritizing, etc.

- Refreshments and Socialization
6. Divide the tasks up among steering committee members.
 7. A few days prior to the meeting, members of the leadership committee, the staff liaison, administration and staff should remind family members of the upcoming meeting. Call family members if phone numbers are known, or ask the staff liaison to do so.

A. Conducting The Introductory Meeting.

It is very important that, if at all possible, members of the steering committee run this meeting. However, if members are hesitant or want assistance, they can ask the ombudsman to assist them in running this meeting or to actually conduct this initial meeting.

Tips for the meeting:

1. Provide a sign-in sheet for names, telephone numbers, e mail addresses, and addresses of family members who attend in order to make future contact and share reminders of the meetings.

2. Distribute the written agenda.
3. Have a member of the steering committee take notes.
4. Follow the agenda distributed in point 2 above. See Chapter 5 for how to run effective meetings.

You may not be able to cover all the items you have listed on the agenda. However, at a minimum, you want to:

- a. Determine if there is commitment to forming a council;
 - b. Establish the next meeting time and date;
 - c. Determine who will lead the group through the next meeting and its initial foundational work; and
 - d. Begin discussion about concerns in the facility and prioritizing what to focus on first (cover this if families are particularly concerned about problems in the facility).
5. Create a sense of excitement and enthusiasm.
 6. Start and end the meeting on time!!! Families have busy schedules and will appreciate having the meeting time clearly defined and followed.
 7. Hand out a copy of this manual to meeting participants.
 8. Ask family members to get involved from the very beginning. If a task is mentioned, see if someone will pitch in and help. Don't have the leadership committee take on everything. Create a team approach.
 9. Tell families to bring at least 3 other family members to the first council meeting.

III. HOLDING THE FIRST COUNCIL MEETING.

A. Preparing For The First Council Meeting.

It is important to carefully plan the first council meeting so that it gets off to a good start.

1. Organize a planning meeting of the leadership committee and any other family members who have volunteered to help. Members can ask the ombudsman to provide assistance both in planning the first council meeting and conducting it. The group should also decide what assistance it would like from the staff liaison.
2. At the planning meeting, the group should:

- a. Develop the agenda for the council meeting. Outline the agenda items, who will be responsible for each item and the approximate time for each item. Keep the meeting to no more than 1 hour or 1 ½ hours.
- The agenda should include a very brief overview of family councils. This is for families who did not attend the introductory meeting and don't know about councils.
 - The agenda must respond to where the group is. It must recognize and meet the needs that were expressed at the introductory meeting (if one was held). For example, if the group identified a problem it wished to address at the introductory meeting, the agenda should include continued processing of that concern.

A sample agenda for this first meeting is outlined below.

Introductions of everyone, including leadership committee	Member of leadership committee or Ombudsman
Welcome from the nursing home administrator and/or department heads	Nursing home administrator, facility staff
Review of what a council is, what it does, benefits of a council, rights of family members	Ombudsman
Review of proposed temporary leadership structure/proposed job descriptions for temporary leaders	Member of leadership committee
Discussion of council mission statement	Member of leadership committee and/or Ombudsman
Discussion of general problem solving approach and how concerns will be communicated to nursing home (See Chapters 3 and 4 for information on problem solving and communication of concerns to nursing home)	Member of leadership committee and/or Ombudsman
Continuation of issue or concern identified at introductory meeting	Member of leadership committee and/or Ombudsman
Establishment of council meeting dates, times, location	Membership of leadership committee and/or Ombudsman
Refreshments and socialization	

- b. Develop proposed job descriptions for each of the temporary leadership positions agreed to at the introductory meeting. These job descriptions do not have to be complicated. Their purpose is simply to provide a clear understanding of the duties included in various leadership positions. See Chapter 3, Section I, A. for description of different duties for leadership positions.

The job descriptions will be discussed and voted on during the first council meeting.

The ombudsman can assist you in developing these descriptions.

- c. Determine how group input will be obtained, priorities set, open discussion facilitated. See Chapter 6.
- d. Identify if there is any training that the leadership committee might find helpful. This could include how to run an effective meeting, leadership and structure issues and effective council advocacy. Talk to the ombudsman or staff liaison about obtaining any necessary training.
- e. Plan an outreach and publicity campaign.
 - Send out an announcement of the first council meeting to all families of residents in the facility and to every one who attended the introductory meeting. Refer to Chapter 2, Section II. A.c. for how to do this. See Appendix 2 for a sample announcement.
 - Refer to other ideas in Chapter 2, Section II. A.c.
 - Refer to Chapter 7 for additional ways to promote council participation.

B. Conducting The First Council Meeting.

1. At the meeting.

- a. Have a sign-in sheet to obtain the names, addresses, phone numbers, and e-mail addresses of families who attend.
- b. Follow the agenda.
- c. Remember to be FLEXIBLE!!

Often families come together as a council because there is a major problem in the nursing home that they are concerned about. When this is the case, the group will most likely want to begin by addressing that concern. This can be an excellent way to begin a group. In this instance, you should decide how you are going to approach problem solving as a council, brainstorm about possible solutions, create a plan of action and act. The council can then cycle back later to work on leadership structure, job descriptions, and mission statement. **The critical element is to start where the group is.**

- d. Be positive, welcoming and upbeat!
- e. Follow the points in Chapter 5 on Running Effective Meetings.

2. After the meeting.

The leadership committee and any families who helped organize the first council meeting should meet shortly after the first meeting. Ombudsman attendance at the follow-up meeting can provide additional feedback and input that could be helpful.

Discuss:

- a. Thoughts about how the meeting went:
 - Overall success;
 - What went well; and
 - What could be done better the next time.
- b. Determine what training/information would enhance leaders' skills. Ask the ombudsman, the staff liaison or someone outside of the facility to provide you with that training.
- c. Plan the agenda for the next meeting.

Your council is off and running!!!!

CHAPTER 3
STARTING A NEW COUNCIL
PHASE 2:
FROM THE FIRST COUNCIL MEETING
TO THE FIRST ELECTION

I. BUILDING THE INFRASTRUCTURE.

In order to be effective the council must develop its “infrastructure.” It is a good idea to do this as early on as possible – ideally over the first few council meetings. However, if family members have more urgent items they wish to address, such as a problem identified by families, then they should start where the group is. This might mean starting with the development and implementation of their problem solving approach and then establishing the other components of council organization later.

Although figuring out the nuts and bolts of how the council will be organized and how meetings will be run may not be exciting or appealing, it is one of the most important things a beginning council can do to ensure success. Without some type of structure and accepted way of doing business, chaos can quickly result and families can become frustrated and leave the council. Certain core elements must be put in place to create a solid foundation for successful council work.

That being said, a council does not need complicated “policies and procedures.” It does, however, need to figure out how it is going to work and how it is going to make decisions. To this end, a beginning council should put the following “building blocks” into place.

A. Leadership and Structure.

The fact of the matter is that the best, most effective councils are run by family members, **not** staff members. This allows the council to be independent and to truly represent the interests of families. Although it may be difficult at first, do whatever you can to ensure that families are the ones leading the council right from the very start.

There is no right or wrong model of leadership; the council should develop a structure that works for its members.

At this point the council has developed some temporary leadership structure to see it through to its first election. The council may wish to make this structure permanent. There is nothing wrong with that if the structure is working.

Listed below is a description of a few models that family councils across the country have found to be effective and successful.¹

¹ Family Councils in Action. Advocacy Center for LongTerm Care.

1. Different Models.

a. Traditional leadership model.

In this model, you find:

A chairperson/president who:

- Runs the meetings;
- Coordinates council activities and programs; and
- Maintains communications with administration and staff.

A vice-chairperson/vice president who:

- Fills in for the chairperson in his/her absence; and
- Performs other duties as determined by the council.

A secretary who:

- Takes notes at the meeting;
- Prepares and disseminates the minutes;
- Maintains a file of all council minutes; and
- Handles council correspondence.

A treasurer who:

- Receives and disburses any council funds;
- Maintains accurate financial records; and
- Reports to the council.

b. Co-chair model.

This model involves sharing offices between 2 members. This can be a helpful model when one person does not want to fill a position alone, but will do so along with another council member. In this way, members can split the duties between them or perform the duties of the office in whatever way works best for them. This model provides moral support and encouragement to those who want to play an active role, but are somewhat hesitant.

c. Leadership committee model

This model involves leadership by a small group of family members who divide up duties among themselves. This model distributes the work among more people and can lighten the load for any one individual. In a small council, everyone could serve on the leadership committee in some capacity. See Appendix 3 for more information about this model.

d. Rotational model

In this model a leadership committee is formed, but leaders rotate the duties among themselves on a regular basis.

2. Important points about leadership and structure.

- a. You can mix and match the above models to form a hybrid that works for your council, or you can create a totally different model. The important thing is to have some system for leadership that is recognized and followed by the council. This promotes more effective organization and lets the nursing home know whom to talk to when it wishes to communicate with the council.
- b. An important key to council success is to distribute tasks and leadership roles as widely as possible among members. This is critical for several reasons:
 - It lightens the load on the leaders.
 - It develops abilities and skills in those who could become future leaders.
 - It is what the spirit of the council is all about – everyone pulling together in the same direction.

Organized strength comes from working together, not from one person doing it all!!

- c. The role of the leadership committee is to work with the council to determine the type of leadership structure the council would like and to oversee the council until elections have been held and new leaders are in place.
- d. As a council changes in size over time, it may need to change its structure.

B. Mission Statement/Purpose.

The mission statement describes exactly what the purpose of the council is and what it is trying to achieve. This mission statement will drive the work of the council. Sample mission statements can be found in Appendix 4.

The council can develop its mission statement in a number of different ways. One approach is to have leaders draft a mission statement, distribute it to members prior to the meeting and then discuss and revise it at the meeting. Another way is to identify and discuss the key components of the mission statement through a group process at a council meeting and then have a subcommittee draft the statement for review by the full council.

C. By-Laws.

The term “by-laws” seems intimidating, but it is really just a fancy name for setting forth how the council will be organized and run. By-laws are also important because they help assure continuity of the council when membership changes. By-laws should address the following issues:

1. Name of the group.
2. Purpose. This is the mission statement developed in section B.

3. Membership. This addresses who can be a member. For instance, can a friend of a resident be part of the council? What about family members whose loved one has died?

Suggestion: A way to maintain continuity in a council is to allow family members of deceased residents to continue their membership for a certain period of time.

4. Officers and committees.

This sets forth:

- The council's officers or leadership positions (i.e. President? Chair? Meeting Coordinator?);
- Who leads the meeting;
- What happens when the leader is absent;
- How committees will be formed (if committees are used); and
- Term limits, if desired.

5. Elections. This establishes the frequency of elections.

6. Meetings. This section states when meetings will be held.

Suggestion: Meeting regularly is very important to the success of a council. It is recommended that the council meet at least monthly. It is also a VERY good idea to meet on the same day of the month, at the same time of day (ex. the third Wednesday of each month at 6:30 p.m.).

7. Rules of order. These rules establish how the meeting will be conducted. Points to cover include:

- Who prepares the agenda for the meeting;
- If the meeting will follow the agenda;
- How the group decides how people who wish to speak are allowed to do so (ex. by raising your hand);
- How decisions are made (for instance – majority vote);
- How disputes will be handled; and
- Whether a quorum must be present to handle the business of the council.

Suggestion: Using parliamentary procedures, or even adapting some of these procedures can help meetings run more smoothly and efficiently. Some councils use Robert's Rules of Order.

Sample by-laws are found in Appendix 4.

8. Instructions for making future amendments to by-laws.

D. Policy For Expressing Concerns Or Suggestions To The Facility.

The council should develop a system that involves placing its concerns or suggestions in writing. This helps to promote accurate communication and permits better tracking and follow up. In cases where the nursing home might not be responsive to council concerns, it also establishes a “paper trail.”

In developing this policy, start by asking the administrator what approach he or she would prefer the council use.

Two possible approaches include the use of a Family Council Action Form²:

Approach #1: Concerns written up on this form are submitted to the appropriate department head for response and action. A copy of the form goes to the administrator. The department head replies in writing to the council. If there is no response or the problem is not resolved, the written form along with the department head response, is submitted to the administrator. The administrator then responds back to the council in writing.

Approach #2: Concerns are written up on this form and submitted directly to the administrator. The administrator routes the form to the appropriate department for response and action. The department head or the administrator replies in writing to the council.

Samples of the “Family Council Action Form are included in Appendix 5.

E. Policy For Ongoing Communication With Administrator and Facility Staff.

The council must have a method for communicating with nursing home administration and staff. Again, a good place to start is to talk with the administrator about what system he or she thinks might work well.

One of the best ways to communicate with the administrator and staff is for the council to meet regularly with the administrator. This meeting could also include department heads. If possible, the meeting should be monthly.

This type of meeting allows both the council and the administrator to keep each other informed about new developments or changes, what they are each working on, what they are concerned about, and how they can work together.

Communication needs to be two-way. Families should inform the administrator of council efforts, needs, concerns, and questions. In turn, the administrator should relay news of the home and/or the long term care system as a whole, and get council input

² This form is from the manual, Family Councils in Action and was developed by the Advocacy Center for Long Term Care.

about any proposed changes in policy, procedures or facility operation that affect families or residents.

Regular meetings help develop a positive working relationship between the council and the nursing home.

If these meetings don't include department heads, the council should consider meeting separately with each department head. One such approach might include meeting with a different department head each quarter.

In addition to face-to-face meetings, other methods of communication with administration and staff include:

- Sending council minutes to the administrator and the department heads; and
- Inviting the administrator and department heads to address the council, share what is going on from their perspective, and answer any questions.

F. Policy For Communication Between Council Members.

The council needs to ensure that members have a way of contacting each other. A system needs to be developed to:

- Inform families of council meetings;
- Communicate with members outside of meetings; and
- Allow families with concerns that arise between meetings to communicate with other council members.

Possible methods of doing this include:

- Creating a private family council mailbox;
- Creating a family council suggestion box;
- Posting the names and telephone numbers of council members who are willing to take calls from other families;
- Making a family council bulletin board with a space on it for families to leave notes to the council leadership or to other members;
- Including the name and phone number of a family council contact person in the admissions packet;
- Developing a phone tree for meeting reminders, and special notices; and
- Developing an e-mail listserve where members can "chat" back and forth with each other.

G. Policy For Communication With Residents.

Since the primary goal of the family council is to benefit residents, communicating with a home's residents is essential. In order to develop such a procedure, resident input should be obtained. This could be done by having one or more representatives of the family council discuss the issue with the resident council leadership. If a resident council doesn't exist, family council members can talk with residents who appear to be particularly active in the home.

Possible methods for communicating with residents are:

- Regular meetings of family council and resident council representatives;
- Appointing someone to serve as the family council liaison to the resident council. The liaison, at resident council invitation, could attend resident council meetings, hear their concerns and report on family council activities; and
- Inviting a representative of the resident council to serve as resident council liaison to the family council.

H. Plan For Handling Individual Family Concerns.

Individual concerns are those which are unique to one person and which are not experienced by other council members. These concerns cannot and should not be ignored, but the key to making progress on issues is to focus on common concerns, not individual issues.

The council therefore needs to develop a policy for addressing the concerns of an individual family member.

Two possible approaches are:

1. Setting aside a limited period of time at each meeting for individual concerns.
2. Creating a small committee to whom an individual family member can take concerns. This committee can provide suggestions for working with facility staff and/or turning to outside assistance if necessary. It can also connect the individual to another family member who may have successfully addressed this issue.

The amount of time it takes to develop the infrastructure will vary from council to council. There is no right or wrong amount of time.

Once these policies and procedures have been developed and approved by the council, it is a good idea to put together a “Family Council Handbook.” This can be distributed to all current members and to all new members as they come on board.

II. PROCESSING PROBLEMS AND COUNCIL ACTIVITIES.

As the council does its organizational work, it will most likely also start addressing family concerns and/or undertaking a project. Information about these two topics is found in Chapter 4.

III. PROMOTING PARTICIPATION IN THE COUNCIL.

This starts from day one and continues forever. See Chapter 7.

IV. HOLDING ELECTIONS.

There are many different ways to hold elections. The following is one way in which elections can be conducted.

A. Before The Elections.

The preparation process for elections should start at least a month in advance of the election date.

1. Develop a system for coming up with a slate of candidates. This can be done by creating a nominating committee or by setting aside time at a council meeting. Whatever approach is taken, it is important to be clear about how council members, or preferably **any** family member, can present nominations. Give families advance notice about the nomination process and deadlines.
2. Ask the selected nominees to write a paragraph about themselves. Distribute the list of nominees along with the candidates' description to council members, and if possible, to all family members prior to the election. Make sure the date of the election is clearly publicized.

B. On Election Day.

1. Conduct the voting by secret ballot at a council meeting.
2. Have a neutral third party, such as the ombudsman, count the votes and announce the new officers.

C. After The Election.

1. Ask the outgoing officers to orient the new officers to their duties.
2. Ask the ombudsman to meet with the new officers to see if they need or want training.
3. Acknowledge the work of the outgoing officers at a meeting and thank them. Give them some token of appreciation, such as a plaque, to recognize their contributions.

CHAPTER 4 COUNCIL WORK

I. PROCESSING PROBLEMS AND CONCERNS (ALSO KNOWN AS PROBLEM SOLVING OR ADVOCACY).

Councils can play a critical role in directly improving resident care in a nursing home. By joining together, families can be a “united voice in a united effort.” As noted earlier, it can be easy to ignore one person; it is much harder to ignore a group of people.

Another name for this type of problem solving work is advocacy. While advocacy may seem scary and intimidating, it is merely a fancy term for identifying a concern, developing a plan of action to address that concern and then implementing that plan.

Below is one approach to processing problems that can be used to bring about success.

A. Bringing Up Concerns.

Each council meeting should have time devoted to concerns. When a member raises a concern during this part of the meeting, first allow him or her to fully explain his or her concerns. Then ask if other members are experiencing the same problem.

*A key to council effectiveness is identifying **common** concerns to work on.*

If the concern that has been voiced is not a common concern, follow the council’s policy for handling individual family concerns.

If the concern is shared by others, see if the group wants to address this concern. In making this decision, council members should ask themselves if working on this problem will improve resident care in some way. If it will, determine if there is enough time to discuss the concern at the meeting, or if members want to put it on the agenda for the next time.

B. Problem Solving Process For The Identified Concern.

Working through the following steps can help make problem solving more effective.

1. Carefully identify the problem.

Answer the following questions:

- What exactly is the concern about?
- Who are the persons involved? Which staff members are responsible?
- When does the problem occur? How often?
- Where does the problem occur? What floor, what wing?
- Why do you think it is happening? What appears to be the cause?
- How long has the problem been going on?
- What has already been done, if anything, to address the problem?

- What do residents say about the problem?
- What do staff say about the problem?

This step also involves collecting as much information as possible about the problem and all the facts that indicate there is a problem. The questions listed above help to gather that information, but there may be other questions to ask as well.

Note: Sometimes the council may find that it does not yet have all the information it needs to proceed with problem solving. It is essential to have “your ducks in a row” and to have the necessary facts to support your statement of the problem. If the council does not yet have specific facts after one meeting, ask members to keep a journal in which they write down details and precise data that support the concern.

2. Develop a concrete and factual statement of the problems.

Use the answers to the above questions and the facts you have collected to put your problem statement in writing.

3. Identify the result the council is seeking.

Determine the council’s goal or objective - what it wants to accomplish.

4. Identify possible solutions.

Explore suggestions for resolving the concern. **Part of the responsibility of voicing concerns is helping to solve them.** Offering creative suggestions, rather than just criticism, will increase the likelihood that your concerns will be heard and treated with respect. It also shows the nursing home that you are a partner in the problem solving process and want to work WITH staff to resolve the issue.

Think about the following questions:

- What might resolve the problem?
- What will it take to fix the problem and to keep it from recurring?
- How many different solutions can be identified?
- What are the pros and cons of each solution?

5. Identify possible obstacles and ways around them.

Consider the obstacles or arguments you might encounter if this solution were to be suggested or tried. Think about how those obstacles could be overcome.

6. Choose the approach the council will try.

7. Develop an action plan.

The council needs to decide HOW it is going to implement the approach it has selected. Determine:

- What steps will be taken?
- Who will be responsible for those action steps?
- By when will those steps be taken?

Record this information in the minutes so that everyone knows what has been decided and who has agreed to carry out certain tasks.

Depending on the nature of the problem, the action plan may simply be to complete the Family Council Action Form. In other cases, particularly if the problem is significant and complex, a more involved approach may be necessary. Such an approach should be handled by 3-4 council members, not just one individual.

Put the issue on the agenda for the next meeting so that council members have to report back to the group about what they have done. This creates a sense of accountability and responsibility that promotes follow-through.

8. Carry out the action plan.

Present your concerns or ideas to facility staff and administration in a reasonable, non-threatening way.

As noted in the previous point, presenting council concerns may be done through the Family Council Action Form. This form is ideal for relatively minor and simple issues. For more complicated problems, the council should consider meeting directly with the administrator or department heads after having provided them with a detailed written description of the problem (that includes the “who,” “what,” “where,” “when,” and “why” information). The council can simply attach this description to the Family Council Action Form.

When meeting with the administrator, consider the following suggestions:

- a. Prior to the meeting.
 - Set up a time to meet with the administrator (or other personnel). Facility staff and administrators are busy people; you will get more time and attention if the visit is planned in advance.
 - Prepare in advance for the conference.
 - Review the written description of the problem and the supporting facts;
 - Write down:
 - the results you are seeking;
 - relevant laws/regulations; and
 - possible solutions to propose!

Suggestion: It is a good idea to have a number of options that you can propose and that would be acceptable to you. This promotes a sense of “give and take” and willingness to compromise that can be helpful. The ombudsman can be an excellent resource in coming up with ideas about possible solutions.

- Ask the ombudsman to help you in writing up the description of the problem with supporting facts or ask him or her to review what you have written. This can be particularly helpful the first time the council addresses a concern.
 - Ask the ombudsman to help you prepare for the meeting and/or to attend this first meeting with you. Again, this can be especially helpful the first time.
 - Take your notes with you into the meeting, as well as copies of any documents relating to the complaint.
- b. At the meeting.
- State the concern and provide specific examples.
 - Be firm, but friendly. Present concerns in a straightforward manner without an accusatory, confrontational style.
 - Start off by assuming that the facility will want to do the “right thing.” For instance, you could say, “We know that quality care is important to you and that you would want to do something about this issue.”
 - Try to create a sense of team: “WE want to work with you to resolve this issue.”
 - Agree on a course of action.
 - Establish who is going to take what steps.
 - Establish time frames for addressing the problem.

Note: allow sufficient time for the facility to take action. Be reasonable, but don’t let concerns be ignored. Depending on the nature of the problem, it might be helpful to ask the facility how much time it needs to correct the problem and then go with that time frame (if that is acceptable). In this way the facility has set its own deadlines.

- Take notes.
- Summarize exactly what was agreed to at the end of the meeting and make sure everyone agrees to the summary. This ensures that everyone has heard the same thing.
- Write a follow-up memo to the administrator (or other personnel) outlining the agreed upon plan of action with time frames. Thank them for their concern and interest in addressing the problem.

Tips on negotiation techniques are included in Appendix 6.

9. Monitor Progress.

- a. If the facility resolves the problem within the established time frames:
- Report this positive result to the council.
 - Make sure the council recognizes and celebrates its success.
 - Make a big point of thanking the facility and acknowledging what staff and the administrator have done. Stress the success you all had in working together. Everyone will feel more cooperative when efforts are appreciated.
- b. If the problem is not resolved within the established time frames:

- Meet again with the administrator and/or staff.
- Determine where the obstacles are and what can be done about them.
- Try to be reasonable and understanding about delays. Sometimes there are issues beyond the facility's control that impact the time frames. (However, if there is *always* some kind of delay or “reason” why the problem is not being addressed, this does not indicate good faith on the part of the facility. See the next section for what to do if the nursing home is not responsive to council concerns.
- Develop a revised plan of action with facility staff; include frequent status reports to keep momentum going for problem resolution.
- Take notes and write a follow-up memo to summarize what was agreed to.
- Give a progress report to the council.
- Recognize steps that have been taken; don't just focus on what hasn't been done.

10. Evaluate the results.

- a. Has the problem been addressed?
- b. If it has, celebrate your success and recognize the work of the facility!
- c. Evaluate your action plan and determine what worked best and what didn't. Talk about how you might do something more effectively next time round and what strategies were most successful.

Note: Don't expect immediate results. Problems that did not develop overnight usually can't be fixed overnight either.

C. When A Nursing Home Is Not Responsive To Council Concerns.

Much of the time concerns can be resolved within the home itself. However, there may be times when this is not the case. At that point, it is time to escalate the pressure on the nursing home.

1. Go further up the chain of command.

Take the council concern to the person above the administrator. This could be the facility owner, the board of directors or a corporate regional director. The council could:

- Ask to meet with this person or group.
- Write a letter to this person or group and send a copy to the administrator. A letter to a “higher-up” sometimes gets the attention of the administrator when other avenues have failed.
- Circulate a petition among family members and send it to this person or group.

If you still don't get satisfaction, try these steps directly with the CEO.

2. Turn to the ombudsman.

Assistance from the ombudsman can take different forms. One approach is for the council to provide the ombudsman with copies of the council complaints/recommendations made to the facility. If the facility is not being responsive,

the ombudsman can contact the administrator and urge him or her to respond to communication from the council.

Council members can also ask the ombudsman for direct help. The ombudsman can make suggestions that the council can then try or go with council representatives to meet with the facility administrator about the problem. Frequently the presence of someone from outside the facility who is knowledgeable about the rules, regulations and facility responsibilities can spur the home into action.

3. File a complaint with the Illinois Department of Public Health.

Each family member can file a complaint, or the council can file a complaint as a group. One attention-getting approach is to organize your members to all file a complaint about the issue on the same day. Include specific details and examples. See *Family Caregivers Guide* published by the Legal Assistance Foundation of Metropolitan and the Evanston Commission on Aging for information about filing a complaint.

However, in addition to filing a complaint about the specific problems, file a complaint about the facility not responding to and addressing council concerns. Remember that federal regulations require that:

When a 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.

In a recent study of family councils in Maryland,³ family members reported that they achieved the most success in problem solving when they:

- Call the ombudsman who elicits a facility response.
- Use meetings and letters.
- Have a constant presence at the facility.
- Communicate continually and constantly remind the facility of the issues.
- Forward written correspondence to the survey agency.
- Have face-to-face meetings with facility personnel.
- Present specific concerns in writing to the administrator.

One family member commented, “They (the nursing home) made changes when given hard facts and demands for our rights. They responded to recommendations when they saw we were sincere and not being pesky and were willing to cooperate.”

³ The Maryland Family Council Project. National Citizens’ Coalition for Nursing Home Reform. Report of Survey Results.

4. File a complaint with the Center for Medicare and Medicaid Services.

This is the part of the federal government that oversees nursing homes receiving federal funding (Medicaid, Medicare).

5. Contact the Office of the Governor.

When contacting the Governor, make sure you indicate the steps the council has already taken and your dissatisfaction with the results so that you don't get sent back to "square one" in the Governor's response.

6. Contact state/federal legislators.

Let your elected officials know about the problems with the care in a particular nursing home and that the system is not working for your loved one. Explain to them the steps you have already taken to correct the problem.

7. Involve the community.

Community members want to know that when they or their family need care, their local nursing homes will provide them with the best care possible. Consequently, those who live in your community can be a source of help to you.

There are several different ways that you can work with your community.

a. Identify an influential individual or group in the community and ask that person or a representative of that group to join you in meeting with the facility administrator. This person could be from a local social service agency, a hospital, or an advocacy group. You might also think about where the nursing home gets its referrals and see if you could work with a representative from one of those entities.

b. Involve your church/place of worship.

Churches/places of worship can be a voice for change in a community nursing home, particularly when its members are residents or it is affiliated in some way with the nursing home. Ask the pastor, minister, priest, rabbi or other religious leader to meet with you and the facility administrator.

c. Take the issue to the city or county government.

Take the concern to the mayor or a representative of the city or county council and ask for his or her help.

8. Contact the Media.

Contacting the media - local newspapers, radio and television stations - can be very effective in bringing about change. Nursing homes are usually very sensitive about their reputation in the community and with the public. Negative media attention about problems and the facility's unresponsiveness to family concerns can create a powerful incentive to fix a problem as quickly as possible.

When working with the media:

a. Make sure you have done your "homework" and that your facts are accurate. If not, you

will lose your credibility and weaken your case.

b. Remember that you can never guarantee how a story will turn out. Your agenda and the media's agenda may not be the same.

Clearly a number of these measures are high profile and should be considered very carefully before being undertaken. A council should weigh the pros and cons of whatever step it takes. Points to consider when doing a "risk/benefit analysis" are:⁴

- Will the benefits of escalating pressure to resolve the problem outweigh the risks of alienating staff and maybe even other family members?
- Do we have the commitment of members behind our plan?
- Will this action help us build the council?
- Will we empower our members and help them to feel that they can make a change?
- Will the work that we do together as a group help our members to feel more connected to each other and to the council?

II. OTHER COUNCIL ACTIVITIES.

Whether or not a council chooses to take on activities other than processing complaints is entirely up to the council. However, since complaint resolution may take time and can sometimes be frustrating, working on other projects can create a sense of excitement and change that can maintain and fuel council enthusiasm. Doing other activities can also lead to improvements in the facility and create a positive feeling toward the council that can assist in complaint resolution.

Below is a list of different activities that a council can organize.⁵ All of these benefit residents, staff and families in some way.

A. Education.

Providing education about a wide range of topics that affect nursing home residents helps families be better advocates for their loved ones.

You will want to select a topic that appeals to the majority of people. When thinking about a topic, consider what families ask about at council meetings or what problems families are experiencing. You can also generate a list of possible topics and have people indicate their preferences.

Possible topics include:

- Asking the administrator and department heads to describe their positions and responsibilities;

⁴ Family and Friends Councils Start-Up Packet. Friends and Relatives of the Institutionalized Aged, Inc.

⁵ Family Councils in Action. Advocacy Center for Long Term Care.

- Asking the pharmacist, physical/occupational therapist, psychologist or other consultant to describe their role and function;
- Asking the administrator to explain the budgetary process;
- Residents' Rights;
- Care planning;
- Long term care regulations and laws;
- How to impact the legislative process;
- Medicaid/Medicare;
- The Illinois Department of Health survey process; and
- Alzheimer's disease.

Once you have chosen the subject, ask family members what they would like to know about the topic, and even to write down specific questions they have.

There are usually a number of speakers who are available free of charge in the community. You can ask the staff liaison and/or the ombudsman to recommend someone to you.

Provide the speaker with the information families want to hear about in advance to help them in preparing their presentation. You will also want to make sure that the speaker knows in advance how long to speak and how long you would like him or her to stay at the meeting.

B. Support.

A facility placement creates feelings of loss, grief, anger, and guilt. Family members often feel overwhelmed and isolated. Joining with others who are experiencing similar feelings can help family members to cope and learn from each other. It is comforting to know that you are not alone and that there are others who understand what you are going through.

In many ways, simply coming together provides support. However, a council can promote this support function by:

1. Setting aside a certain amount of time at each meeting.

During this block of time, members can talk about their personal feelings and problems.

Note: It would be best to do this toward the end of a meeting.

2. Creating a formal support group that meets separately from the council.

Support groups and family councils are two different types of entities that should not be combined into one because their functions are not identical. However, starting a support group for interested family members might be a project that the council could undertake. It could do this by looking for a trained facilitator or by training one or more of its own members to lead the support group. You might be able to obtain training in support group facilitation by contacting organizations such as the Alzheimer's Association.

C. Orientation For New Members.

Since most of us have never spent much time in a nursing home, placing a loved one in a facility for the first time can be very confusing and bewildering. Connecting with people who have been through the experience before can help families and their loved ones get off to as smooth a start as possible.

However, in order to provide orientation to new members, the council must know who the new members are. The best way to find this out is to ask the facility to provide the council with the names and phone numbers of new family members. If the facility is concerned about confidentiality, the facility can ask new families if they would like to have their name, phone number, and address released to the council. If so, the family can simply sign a consent form. A sample form can be found in Appendix 7. Other ways to connect with new families include:

- Asking all council members during their nursing home visits to make a point of greeting any families they have not seen before;
- Posting a sign welcoming new families and urging them to contact the family council president (whose name and phone number are listed on the sign);
- Having a family council bulletin board;
- Developing a council brochure and having the facility place it in the admissions packet; and
- Placing family council information in the lobby.

Ideas for orientation projects include:

- Holding an orientation meeting for new family members. The frequency of the orientation will depend on how often new residents are admitted to the home.
- Creating a welcoming committee whose members contact new families through a letter and then a follow up phone call.
- Developing a family council mailbox for notification of new residents' names and room numbers and family member information.
- Writing a pamphlet or booklet introducing new families to the nursing home and the council. This information could be provided in the admissions packet or be available in the facility.

D. Monitoring Nursing Home Conditions.

In addition to monitoring your loved one, family members can keep an eye out for the general well-being of other residents as well. This does NOT mean that council members should violate residents' rights to privacy, or that they should do anything that is invasive. It simply means keeping your eyes open to what is going on around you.

The council can educate itself about what good care in a nursing home looks like. Information is available in [the Family Caregivers Guide published by the Legal](#)

Assistance Foundation of Metropolitan Chicago and the Evanston Commission on Aging and from the local ombudsman.

Note: This information will help individual family members be more effective advocates for their own loved one too.

Monitoring might include:

- Checking on other families' loved ones when you are visiting and letting them know if you see anything of concern; and
- Noting the condition of other residents you might see on the unit and letting staff know if you observe anything of concern.

In essence, you can form a sort of "neighborhood watch."

E. Projects

Listed below are just a few of the projects that councils have successfully undertaken:

1. 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;
- Set up a buddy system for family members and residents. Visit your buddy's family member when your buddy is on vacation or sick; and
- Engrave all dentures and eyeglasses.

2. Projects to strengthen relationships between administration, staff, residents and the council.

- Organize staff recognition and appreciation events. Examples include having time clock breaks with homemade cookies or holding a pizza party;
- Cooperate on joint projects with the resident council; and
- Sponsor activities and events enjoyable to both residents and families.

Suggestion: Organizing a staff recognition and appreciation event can be a very good project for building a positive relationship with nursing home staff. If the facility has been "leery" about the formation of a family council, it might smooth the waters to begin council work with this type of event.

3. Projects benefiting families.

- Complete a family guide about the nursing home;
- Create a lending library of books and pamphlets relative to aging, specific health problems, etc.;
- Sponsor a family support group; and
- Develop a speakers program.

3. Projects involving fundraising or donations.

Raise money for:

- A microwave for warming meals or snacks;
- A vegetable or flower garden; or
- A wheelchair accessible van.

F. Department of Public Health Surveys.

All nursing homes are inspected approximately annually by the Illinois Department of Public Health. When the inspectors (called surveyors), conduct their inspection they want to know how families feel about the care and services provided by the nursing home. Members of the family council can ask to talk with the surveyors when they are in the building (a sign on the facility door will let you know when the surveyors are on-site). While surveyors are not required to meet with family councils, many do. If a meeting with the entire council is not possible, the family council president or other family representative can talk with surveyors about council concerns.

It is a good idea to learn about the survey process and how the council can best convey its concerns to the surveyors. The ombudsman can provide you with this information and can help you prepare for a meeting with the surveyors.

Since you will not know in advance exactly when the surveyors will be in the facility, it is helpful to set up some type of “phone tree.” When anyone in the council learns that an inspection is taking place, he or she can immediately contact another member, who contacts another, and so on.

Prior to meeting with the surveyors, write out any problems or concerns the council has. Remember to provide as much specific information as possible (i.e. “who,” “what,” “where,” “when,” and “why”). When you meet with the surveyors, give them a copy of your concerns, as well as council minutes or any other documentation that supports those concerns.

Once the facility survey report is available, the council can review the results, which must be available in the nursing home. You may want to consult [the Family Caregivers Guide published by the Legal Assistance Foundation of Metropolitan and the Evanston Commission on Aging](#) to learn how to read an Illinois Department of Public Health survey and/or ask the local ombudsman to talk with you about how to interpret the results. The council can then monitor the facility’s correction of identified problems. If the problems appear to continue, the council should talk with the administration, the ombudsman, and the Department of Health.

G. Public Policy Advocacy.

There are times when a council will find that a problem it is trying to resolve is so widespread or endemic, that a more global approach must be taken. The council may find that putting “band aids” on a problem doesn’t work very well, and that a more lasting solution must be found. For instance, while the council may try to raise money to

cover personal items for residents on Medicaid who can't afford them, and while this is a wonderful council activity, the council is never going to be able to sufficiently help every one who needs assistance. The problem needs a systemic solution; for example, the amount of money that all residents on Medicaid are allowed to keep should be raised from the current amount. This involves changing existing laws and/or regulations.

Council members are in a good position to be able to speak to the need for changes in legislation, regulation or policy. There is no more powerful testimony than a consumer who has direct experience with a particular problem.

To change laws on the national level, council members can contact their U.S. senators or representatives.

However, the majority of councils that become involved in public policy advocacy do so at the state level. If your council is interested in legislative action, it may be a good idea to form a legislative committee.

Start by educating yourself about the legislative process in Illinois. Invite someone from an active consumer advocacy group to your meeting to provide you with an overview. (In fact, you may want to begin your legislative work by partnering with another group that has more experience.)

Below are a few suggestions for pursuing legislative change:

Clearly define the change you are seeking and put it in writing. Find as many examples as you can to support your case for a change.

- Contact legislators for support long before the legislative session begins.
- Seek support from other groups and individuals.
- Get residents and other families to tell their stories.
- Meet with key legislators.
- Conduct a letter writing campaign.
- Get media coverage.
- Contact the Governor's office.
- Keep up-to-date on what is happening with the bill. Develop a way to get an "alert" out quickly if you need supporters to contact legislators.
- Show appreciation for all those who worked on the bill – even if it doesn't pass!

CHAPTER 5

KEYS TO SUCCESS: RUNNING EFFECTIVE MEETINGS

Effective, well-run meetings are essential to a council's well-being. There is no faster way to destroy a council's energy and focus than to have chaotic, disorganized and frustrating meetings!

Successful meetings result from hard work before, during and after a meeting. Tips for holding effective meetings are outlined below.

I. ESTABLISH GROUND RULES.

Establish some "ground rules."⁶ These can help to promote good communication without hurt feelings. Examples of some ground rules are:

- Discussions are confidential and should not be shared with others outside the council meeting.
- Set a time limit for meetings and keep to it.
- Discuss IDEAS at meetings, not individuals.
- Protect resident privacy by not discussing specific medical problems and by not mentioning residents' names if possible.
- If disagreeing, do so with respect.
- If disagreed with, do not take it personally.
- Only one person should speak at a time – others should be listening.
- Everyone's input has value and should be acknowledged.
- Discuss one topic at a time.
- Use facts, not assumptions.

II. USE COMMITTEES.

Use committees if the council meetings become too long. Committees allow the council to move forward on projects and issues, without having to spend hours on the details. Council time is spent hearing the committee report and acting on committee recommendations. If the idea of committees is not appealing to family members, you can simply ask for someone to take the lead in coming up with some ideas in an area and ask if there are others who would help that person. Families may feel less intimidated by this approach.

⁶ Centralina Area Agency on Aging/Ombudsman Program: Family Council Guidebook. 1999.

III. PREPARE FOR THE MEETING.

The groundwork for effective meetings starts with the development of an agenda for the meeting. The organization, “Friends and Relatives of the Institutionalized Aging” (FRIA) recommends that whoever is responsible for preparing the agenda:

- Review the minutes from the previous meeting to remind them what items were postponed, what was to have been done between meetings, and what needs to be reported on.
- Organize the agenda in terms of new/old business.
- Indicate the responsible person and time frame for each item.
- Make each agenda specific to the meeting.
- Put the most important information in the middle of the agenda since that’s when most people will be there.
- Include time for concerns to be raised/discussed.
- End on a positive note.

See Appendix 8 for sample council meeting agendas.

Distribute the agenda at least one week prior to the meeting:

- Post it at the nursing home.
- Send it to members.
- E-mail it to members.
- Have copies available to pick up at the facility.

IV. TIPS FOR CONDUCTING THE MEETING.

The meeting leader is primarily responsible for seeing that meetings go well. The leader should:

- Have a sign-in sheet to collect names, addresses, phone numbers and e-mail addresses of participants.
- Start on time.
- Post ground rules during meetings.
- Introduce meeting participants, especially those attending for the very first time.
- Ask people to raise their hand when they wish to speak.
- Ask people to speak in the order in which they raised their hand.
- Be firm about sticking to the agenda. When members raise issues that are not on the agenda and there is no time for discussion, ask them if they would like the issue to be taken up at the next meeting.
- Be firm about time frames without cutting off good discussion. If an item takes longer than planned for, members can vote to continue the discussion and postpone other agenda items.

- Ask for the opinion of silent or less active members. Those who are shy may be overwhelmed by those who dominate the group. The leader can do this by saying, “We’d like to hear from everyone. Would anyone who hasn’t spoken like to comment?”
- Periodically summarize what has been said and ask for additional input. For instance, the leader can say, “We have 3 ideas for involving new families. Does anyone have a fourth idea?”
- If members debate among themselves and the debate is not pertinent to the discussion, ask them to continue their discussion after the meeting.
- When there has been sufficient discussion on a point, move the group toward action:
 - Determine the steps needed for action; and
 - Determine who is responsible for each step and time frames for those actions
- When tasks are identified that need to be done, ask members who will take on that task. If no one volunteers, ask two people if they would see that it gets done. Try to match skills of individuals to needs of the council.

V. KEEPING THE MEETING ON TRACK.

The following are suggestions for how to structure time for family input at council meetings so that members can share their experiences and issues, but not take up the entire meeting on any one item.

Note: The leader should suggest the proposed structure before beginning the discussion so that everyone understands and agrees to the approach being used.

A. Timekeeper.

Establish the amount of time that each person will be allowed, then appoint a timekeeper with a good sense of humor who can watch the clock and let people know when their time is up

B. Use parliamentary procedures or some established guidelines for guiding discussion.

C. Notecards.

Give people notecards to submit their feedback or most important issues. You can then sort the cards and form committees by issue.

D. Sentence limit.

Have the group agree upon a limited structure for expressing issues. For example, “in five sentences or less, describe the most important issue you think the council should work on.”

VI. AFTER THE MEETING.

- Prepare minutes and distribute prior to the next meeting. See Appendix 9 for sample minutes.
- Periodically evaluate the effectiveness of the meetings. Do this formally through a written survey and informally by asking members after meetings. Implementing their suggestions will make members more likely to feel comfortable voicing any suggestions for improvements they might have.

CHAPTER 6

KEYS TO SUCCESS:

TECHNIQUES FOR PRIORITIZING ISSUES, GATHERING INPUT, AND BRAINSTORMING AT MEETINGS

Group process and group decision-making are critical to successful council work. This chapter provides you with some suggestions for how to use a democratic approach to guide the council's work.

I. PRIORITIZING ISSUES.

One possible approach is outlined below.

- Ask members to each write down 3 things they would like to have changed about the home. (You can obviously use this for other issues besides changes people would like to see in the home.)
- Collect the papers and write all the ideas on a flip chart. Do not duplicate similar ideas. Do not indicate which ideas were listed by more than one member.
- Ask each member to choose the three items they feel are most important for the council to address. Have everyone rank their three issues, marking "10" for their highest priority, "7" for their second priority, and "3" for their third priority.
- Collect the rankings and calculate a cumulative score for each item on the flip chart.
- Create a family council priority list ranging from the highest scored to the lowest scored item.

II. GATHERING INPUT AND MAKING DECISIONS.

You can try the following method:

- Ask everyone to come up with a list of their own ideas on a particular topic or question.
- Go around the room and ask each member to name something from their list. Write that item on a group list.
- Once the group list is developed, vote to select the topic or issue.

This approach gives everyone a chance to participate and the combined list will represent the best thinking of everyone.

III. BRAINSTORMING.

Brainstorming is when a group throws out as many ideas as possible, without discussing the merits of any one idea.

Steps include:

- Writing down each idea on a flip chart as it is presented.
- Discussing each idea.
- Rejecting ones that the group does not think are appropriate.

- Narrowing the list down to the best choices.
- Voting on the idea to be selected.

CHAPTER 7

KEYS TO SUCCESS: PROMOTING PARTICIPATION IN THE COUNCIL

To develop, grow and maintain a council, you must promote it enthusiastically and continually **from the very beginning**.

Ideas for promoting a family council include:

- Designing a brochure about the council and asking the facility to include it in the admission packet. Be sure to include a contact person's name and number.
- Setting up a welcome table on a weekend day in the lobby to introduce visiting families to the family council and to hand out materials.
- Taking turns being responsible for calling members to remind them of an upcoming meeting.
- Posting flyers about the family council and its next meeting in the facility.
- Developing a family council poster and hanging it in the facility.
- Creating buttons for members to wear that say something like, "Ask Me About Our Family Council!" or "Ask Me How You Can Make A Difference in Residents' Lives!"
- Establishing a buddy system with new families by asking the facility to get permission from new families at admission to release their phone number to the family council. A current council member then "adopts" the new family member.
- Using "wing representatives" to recruit new members and advertise meetings. Families who visit frequently and for long periods of time may be ideal for this role.
- Developing a family council newsletter and asking the facility to send it to all family members (or ask for donations from families and have the council send it or ask that the newsletter be included in other facility mailings, etc.).
- Using a sign-in sheet at meetings to gather names, addresses, e-mail addresses, and phone numbers. Use this information to remind members of upcoming meetings either by phone or by e-mail.
- Putting notices in the nursing home's newsletter.
- Publicizing information about the council in local newspapers, periodicals, television or radio.
- Posting notices on cars outside of the home.
- Asking the long term care ombudsman to recommend the council to family members who contact him or her.
- Personally inviting any new family member you meet in the facility.
- Mailing an announcement about the next council meeting to all members, and preferably, to all families. Ask the nursing home do this mailing for you. (If the facility can't or won't do a separate mailing, the council can do this or request that the facility include notification about family council meetings with monthly billing statements sent to families.) See Appendix 10 for a sample council meeting notice.

- Making arrangements with the social worker or the administrator to get regular updates of new families' names.
- Sending a welcome letter to each new family and following this with a call. See Appendix 11 for a sample welcome letter.
- Placing the name and phone number of a family council contact person at each nurse's station and in the lobby.
- Requesting a special family council bulletin board in a central location.
- Asking the facility social worker or other staff person who meets with families upon admission to tell families about the council and urge them to attend.
- Sending out regular updates to family members.
- Walking the halls at different times with a handout or brochure about the council.
- Sponsoring an activity such as a tea or a cookout.
- Holding a membership drive.
- Publicly thanking members who have taken an active role and congratulating those who have done good work.
- Celebrate and publicize council successes.

Keep in mind that the number one reason people volunteer their time in any type of organization is because they were asked!!!

CHAPTER 8 BUMPS IN THE ROAD

I. DEALING WITH OBSTACLES TO COUNCIL DEVELOPMENT.

In February 2000, the National Citizens' Coalition for Nursing Home Reform conducted a survey of family members, ombudsmen, and nursing home facility personnel in Maryland to gather information about their particular experience working with family councils. The survey identified many obstacles to family council development, as well as many successes and positive contributions made by family councils (see Chapter 11 for "Family Council Successes").

The table below outlines the obstacles identified in the project, along with some possible solutions.

OBSTACLE	POSSIBLE SOLUTIONS
Family members lack time	<ul style="list-style-type: none"> ● Begin and end meetings on time. If family members see that meetings are efficient and purposeful, they will be more likely to come to future meetings. ● Share leadership responsibilities and delegate small tasks to members so that the time commitment for individual members is not too substantial. ● Make use of agendas to keep meetings on track. ● Schedule meetings at times that are convenient for family members.
Family members lack interest	<ul style="list-style-type: none"> ● Introduce yourself to other family members on your loved one's unit. Ask them about how they've felt about the care provided to their loved one and any ideas they have about needed improvements. Family members will respond to a personal invitation more readily than a letter or flier. ● Explain the rights of family councils to other family members and the potential that family councils have to promote improvements at the home. ● Introduce the concept of a family council in a positive way. Family councils can be useful for advocacy as well as information sharing and support. All nursing homes have room for improvement and new ideas.
Family members fear retaliation	<ul style="list-style-type: none"> ● If family members are reluctant to be seen at family council meetings, discuss the possibility of meeting off-site so that family

	<p>members will feel more comfortable coming to meetings.</p> <ul style="list-style-type: none"> ● Explain that family council members give each other support and strength. Also point out that issues or concerns will be presented to the facility administration as a group, not an individual, concern. <p>Present the family council positively to both family members and nursing home personnel.</p>
Council members get discouraged easily	<ul style="list-style-type: none"> ● Pick both short and long-term “achievable” goals so that the council can see concrete progress. Make sure that council goals are firmly rooted in the common concerns and interests of the members. ● Meet at least once a month to assure continuity and ability to identify goals and work toward them.
Family members lack information and education	<ul style="list-style-type: none"> ● Contact NCCNHR with questions or need for guidance. ● Use the ombudsman program as a resource. ● Ask the facility to arrange for speakers of interest.
The family council experiences resistance from the nursing home	<ul style="list-style-type: none"> ● Have a few leaders meet with nursing home management separately to introduce the council and its purpose in a positive manner. ● Communicate constantly and try to respond positively to concerns the facility may have. ● Know the rights guaranteed to family councils by federal regulations. ● Seek the assistance of outside agencies if necessary. ● Discuss and come to clear agreements with facility personnel about what can be accomplished and expect that personnel will follow through on those commitments. Follow up on verbal communication with communication in writing to prevent misunderstandings.
Difficulty getting names of other family members	<ul style="list-style-type: none"> ● See above for suggestions on how to work with the facility. ● Start a “buddy system” where council members greet new families and invite them to council meetings. <p>Keep a sign in sheet for each meeting and gather contact information.</p>

For more information, contact:

Gail MacInnes or Elma Holder, National Citizens' Coalition for Nursing Home Reform, 1424 16th Street, NW, Suite 202, Washington, DC, 20036, tel. 202-332-2275, fax. 202-332-2949, e-mail: gmacinnes@nccnhr.org or eholder@nccnhr.org, website: <http://www.nccnhr.org>.

II. DEALING WITH COMMON PROBLEMS THAT ARISE DURING COUNCIL MEETINGS.⁷

Councils can also encounter problems once they have formed. Here are some strategies for dealing with some typical family council problems.

Problem 1

Somebody states that meetings are a waste of time and that nothing ever gets accomplished. The council and the council leadership are criticized.

Approach:

- Don't get defensive.
- Acknowledge that person's opinion and agree to disagree.
- Invite the person to be more active – give them a concrete task that fits their area of concern. For example, the group leader can say, "You seem like someone who has many good ideas about how to improve nursing care and a lot of energy. We need people like you to make the council stronger. Why don't you join our nursing committee?"
- Invite the person to submit specific suggestions for improving the meeting.
- Don't get drawn into a debate. Move on and offer to speak after the meeting.

Problem 2

Person spends the entire meeting on their individual issue and takes up lots of time with his or her situation.

Approach:

- Follow the council's policy on handling individual concerns.
- Refer the person to appropriate nursing home staff.
- Refer the person to the long term care ombudsman.
- If the individual issue is a common concern or recurring group concern, put it on the agenda for the next meeting. Give the individual sources for help in the meantime.
- Kindly, but firmly, explain that the meeting needs to cover the items on the agenda and that the leadership could meet for a short time after the meeting to brainstorm with the person about possible suggestions.

⁷ Family & Friends Councils Start-Up Packet. Friends and Relatives of the Institutionalized Aged, Inc.

Problem 3

Family member feels discouraged and hopeless about making any changes. Comments during the meeting in a negative way that serves to discourage others.

Approach:

- Validate the person's feelings. For instance, you might say, "I know sometimes we all feel very discouraged. It's difficult to see your loved one suffer and to feel like there's nothing you can do to help."
- Offer family council work as an effective way of making change together with others who understand their feelings of discouragement. Many times people have gotten nowhere with individual advocacy, but have not tried advocating within a group.
- Highlight any past successes the council has had.
- Talk about success as a result of being organized and having committed members who are willing to do work.

Problem 4

One family member dominates the meeting and others have a hard time getting a chance to express their opinions and ideas.

Approach:

- Use the meeting procedures laid out in the by-laws.
- Ask silent members for their thoughts.
- Set time limits for individual comments on any one topic.
- Speak privately with the person if necessary.

Problem 5

Person is off topic and is not following the group discussion or agenda.

Approach:

- Gently say, "What you're saying is important, but I'm not sure how it relates to the topic of discussion which is Could you please make the connection clear?"
- Redirect speaker to more appropriate section of agenda. "It seems like your concern or comment is more applicable to point number 3 on our agenda. Could you hold your comment until then?"

Problem 6:

Person interrupts others and speaks out of turn.

Approach:

- Use the method of participation established in the by-laws (for example, members shall raise hand and be recognized by chair"). Refer to these mutually agreed upon procedures when members get out of line.
- Don't allow people to interrupt one another. Step in quickly and respectfully.

**A FINAL NOTE ABOUT STARTING
A FAMILY COUNCIL**

Remember that it takes TIME!!!

One member of a new family council recounts their approach:

“Our attitude is that any business takes a start-up period. We’re a little business and we have to run like a little business, and we have to have people who persevere rather than get discouraged. We’re making inroads: We have a forum; we have strong representation; our materials are out there and seen. We have a good core membership, direct communication with the administrators and managers, and there is some improvement in response to individual concerns. But there are a lot of problems that we have not successfully approached. But we persevere. We pay attention to detail. We do not treat the council like a club. We’re totally self-determining and self-organized. We instruct our members to be more proactive. We really have to keep chipping away.”

From: Family Education and Outreach: Final Report. A Project of the National Citizens’ Coalition For Nursing Home Reform.

CHAPTER 9

MAINTAINING THE COUNCIL

It takes constant work to maintain an ongoing active council. Some important ways to do this include:

- Recruit! Recruit! Recruit!
- Promote council participation all the time! See Chapter 7 for detailed ideas on how to do this. If you've tried one approach and it hasn't worked, try something different.
- Arrange for the immediate welcoming of new families. See Chapter 4, section II. C. for ideas on how to do this.
- Communicate effectively with staff.
- Periodically review your system for communicating with staff to see if it is working for families and staff.
- Make it a point to meet new department heads. Invite them to a council meeting.
- Host staff appreciation events.
- Ask to participate in new employee orientation to present the family perspective.
- Periodically review the mission statement to make sure it still reflects council goals.
- Replace departing officers quickly.
- Constantly work to develop new leaders.
- Consider "succession planning," i.e. having the vice president automatically be in line to run for president so that he or she will already be familiar with the organization and a leadership role.
- Don't overburden any one member of the council with council work.
- Track attendance at council meetings. Call family members who have not attended a meeting to tell them their presence was missed. Report what happened at the meeting and tell them that you hope to see them at the next meeting.
- Periodically review, and if appropriate, change council priorities.
- Encourage family members to communicate directly with council leadership. Get a private family council mail box or a private suggestion box in the facility.
- Build council spirit:
 - Appoint a "Coordinator of the Health and Welfare of the Council." Assign one or more people to keep an eye on council morale and to arrange "pick-me-ups."
 - Establish traditions. These help to create a sense of unity and solidarity.
 - Create a logo or motto for the council to foster a sense of team.
 - Hold a social event such as a potluck dinner.
- Celebrate council successes:
 - Publish an "annual report" that states your accomplishments for the past year.
 - Keep everyone up to date on where you are with council projects – this helps keep momentum going and provides impetus to continue moving forward.
- Be on the look out for new ideas and new projects.
- Ask the ombudsman to come in and speak to the council about what other councils in the area and nationally are doing.

- Choose a sister council to share ideas with.
- Gather input for project ideas from staff and residents.

CHAPTER 10

STRENGTHENING THE COUNCIL

The first step in strengthening your council is to try to determine where the council's weaknesses lie. Once the problem areas have been identified you can focus on the appropriate "remedy."

I. EVALUATE YOUR COUNCIL.

Start by having the entire council complete the Council Evaluation Quiz at a council meeting. The quiz is found in Appendix 12.

II. ANALYZE THE QUIZ RESULTS.

A. Do An Initial Analysis.

Ask each person to count up the total number of points based on the following point system: each "yes" answer is 2 points; the bonus question is worth 16 points.

Determine the average score for the council by totaling all the scores and dividing by the number of tests included in the count. A score of 50 or less may indicate council weakness.

B. Do Further Analysis If There Is Possible Weakness.

Ask for a volunteer to do a more in-depth review of the results by figuring out the average number of "yes" and "no" answers per category. Rank the "yes" and "no" categories in descending order – from the most number of "no's" and the most number of "yes"; to the fewest. This can be done between meetings and the information distributed to members prior to the next meeting. Ask members to come prepared with ideas about what issues to address and possible solutions.

C. Applaud Council Successes.

At the next meeting, the council should discuss the more in-depth analysis. Begin by looking at the "yes" answers and congratulating yourselves on the good work you have done! Celebrate and applaud that accomplishment; it is very important to acknowledge where the council has been successful.

D. Decide Where To Focus Council Improvement Efforts.

Next, look at the categories with the greatest number of "no" answers. These indicate areas where the council could be strengthened. Decide which category you wish to address first. This could be the largest category or one of the "top three."

E. Develop And Implement An Action Plan To Address The Area.

There are different ways in which members can work to strengthen an area of weakness. One approach is to use the following problem solving process:

Note: Consider having the ombudsman or an outside facilitator help you with this process.

1. Identify exactly what it is in that category that is problematic.
2. Conduct an inclusive brainstorming process to come up with ideas for addressing those specific problems.
3. When considering how to strengthen an area, start by going back to the basics in that particular category. For instance if the category with the greatest number of “no’s” is that of “Council Infrastructure/Organization,” revisit that section in this manual. If most of the problems lie in the category of “Council Meetings,” look at that part of the manual. Are there ideas in this section that the council has not yet tried or not fully implemented?
4. Ask the ombudsman for suggestions based on his or her knowledge of the council’s efforts to-date and successful models he or she has seen in other councils.
5. Ask the ombudsman to connect you with family council members in other facilities so that you can learn how they have addressed this issue.
6. Call individuals identified on the Resource List in Appendix 13 and ask them for suggestions.
7. Once you have decided on what is to be done, determine who will be responsible for those steps and the time frames.
8. Write up the “plan of action” and distribute it to all council members so that everyone is very clear about what was agreed upon.

The plan of action should include:

- General area to strengthen;
- Specific problems to address;
- Goals; and
- Specific action steps (what is to be done, who is responsible, due date).

E. Evaluate The Success Of The Action Plan.

1. Evaluate the success of the plan of action at the end of the established time frame. If the council has been successful, it should move on to address another issue.

2. If the council has not accomplished its goal, it should reevaluate and revise its plan of action. Again, the ombudsman may be able to provide suggestions or may be able to connect your council to other family councils that may have successfully dealt with this problem.

Note: It may be possible to address more than one area at a time, but be careful not to take on too much at one time.

CHAPTER 11

FAMILY COUNCIL SUCCESSES⁸

There will be ups and downs in the development and maintenance of a strong council. Keep in mind that the hard work is well worth it for the improvement you can make in the lives of residents, staff and families!

Family councils can make a difference and are doing so all the time!! Here are just some of the success stories from around the country:

- A family council's expressed concern about mouth care resulted in a staff in-service training on mouth care for staff.
- A meeting with facility management improved staffing assignments and stopped staff rotation.
- A family council did its own survey about family member concerns, issued a report, met with management and regional corporate representatives about concerns. As a result of the meeting, some improvements have been made.
- Family council advocacy resulted in better services to residents such as food (more of their preferences) and daily care (more individualized to residents such as bathing, activities at specific times of the day).
- A family council persuaded the administrator to require staff to put date/time on resident disposable briefs when changed.
- The facility agreed to provide towelettes and to direct staff to wipe residents' hands at meals.
- One council got grievance/commendation forms at each nurses' station and drinks at each bedside.
- Family councils sponsored staff appreciation and educational programs.
- One council worked out billing/delivery issues with the facility pharmacy representative for the nursing home.
- A family council got a family council notice board, and notice of the family council in admission packets.
- One council kept a notebook list of concerns, date addressed, plans by the facility to rectify/resolve the issue, and date of completion - the council reviews the list monthly for continuation.
- A family council conducted a staff appreciation event.
- Family council meetings opened communication lines with family and staff and offered some support to the families.
- Family council meetings provided an opportunity to meet in an open forum and discuss issues honestly.
- Family council efforts improved education and communication between families and facility.

⁸ Maryland Family Council Project. National Citizens' Coalition for Nursing Home Reform. Final Report.

- A family council developed a program to provide support to families during a resident's dying process.
- Educational programming is routinely scheduled to meet the caregiving needs and personal interests of the council members.
- A family council sponsored an annual Christmas party for staff's children.
- A family council initiated an Employee of the Month recognition project.

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Would you like to meet others sharing similar experiences to you?

Are you interested in working with other families and the nursing home to enhance the quality of care and life for residents?

Would you like to voice your opinion on nursing home issues?

Please join us in organizing a Family Council!

INTRODUCTORY MEETING

DATE:

TIME:

LOCATION:

For more information, contact:

Dear Family Member:

We cordially invite you to attend the first meeting of the Family Council here at name of facility.

The purpose of a council is to bring interested relatives and friends of residents together to discuss common concerns and work with the nursing home to take action for positive change aimed at enhancing the environment and quality of life of the residents.

By joining the council you can meet others who share your experience and desire to make name of facility an even better place for our loved ones to live and for staff to work.

FIRST COUNCIL MEETING

DATE:

TIME:

LOCATION:

If you have any questions, feel free to contact member of leadership committee or other family member.

We hope to see you on date!!

Sincerely,

NEGOTIATION TECHNIQUES

Negotiation involves bargaining with another party to arrive at a binding agreement.

In negotiations, it is critical for you to know:

1. whom you are representing
2. what problem you want to solve, and
3. what may be acceptable solutions.

Negotiation should not be entered into without knowing what can and cannot be done by all parties to achieve the desired results.

When you plan to negotiate in a formal session:

1. Prepare an agenda so that you do not get sidetracked from the items you want to discuss.
2. If the facility spokesperson promises that certain things will be done, you should ask for a timetable by which they will be carried out.
3. If the solution to a problem involves a change in facility policy or is dependent on promises made by the facility, ask for a written agreement.
4. It is always a good idea to follow any formal session with a letter summarizing the results.
5. Any actions agreed to should be monitored to determine if, in fact, the changes are made.

An excellent resource on negotiation is the book titled, **Getting to Yes**. This book discusses the strategy of **principled negotiation**. Following are the key elements of principled negotiation:

- Negotiate on the merits.
- Recognize that the participants are problem-solvers.
- Concentrate on achieving a wise outcome, reached efficiently and amicably. To do this, you must:
 - Focus on solving the problem.
 - Refrain from trying to score debate points or outsmart the other party.
- Separate the people from the problem.
 - Be soft on the people, hard on the problem.
 - Proceed independent of trust.
 - Be aware that the other person probably perceives the situation differently than you do.
- Do not react to emotional outbursts. Let the other side let off steam.
- Phrase your proposals in terms of what you think will solve a problem, not in terms of what they should do.
- Focus on interests, not positions.
 - Explore interests.

- Realize that each side has multiple interests. Try to find compatible ones that can form the basis of a solution.
- Avoid having a bottom line.
- Invent options for mutual gain.
- Develop multiple options to choose from; decide later.
- Look for solutions that allow both sides to gain something, in contrast to compromises where both sides lose something.
- Try to develop a win-win solution based on shared interest.
- Insist on using objective criteria.
 - Try to reach a result based on standards independent of will such as laws, written rules, outside experts.
- Reason and be open to reason; yield to principle, not pressure.

Much of the success of your negotiation will depend on your preparation. It is necessary to have a very clearly defined negotiating position. One of the easiest ways to come up with a negotiation position is to decide what it is that the council is actually prepared to accept as a settlement for the issue. This decision needs to be made by the whole council or as many people as possible. It is also important that all of the members of the council have a sense of what can really be accepted as a settlement so that they don't feel the negotiating members have "sold out" when they compromise on the initial demand.

Sample Consent To Release Name Form

I hereby authorize and request _____ to release my name, address and phone number to a representative of the family council for purposes of contacting me.

Date

Signature

FAMILY COUNCIL SELF-EVALUATION QUIZ

Put a “yes” or “no” next to each question based on your honest opinion of the council.

I. COUNCIL INFRASTRUCTURE/ ORGANIZATION

1. Does your council meet regularly?
2. Does your council meet at least monthly?
3. Is your council led by family members?
4. Does your council have leaders elected by family council members?
5. Does your council have a written mission/purpose and bylaws?
6. Are minutes kept of meetings and retained?
7. Are announcements of meetings and council minutes posted or readily available?
8. Is there an established system for communicating concerns to the nursing home administration and staff?
9. Do council representatives meet on a regular basis with nursing home administration?

II. COUNCIL MEETINGS

1. Are meetings held in an environment that is conducive to discussion?
2. Do meetings have a planned agenda and do all participants know what is on the agenda?
3. Are meetings on track and focused?
4. Are members' opinions respected?
5. Are meetings a good length of time?
6. Do staff and administration attend only at council invitation?

III. FAMILY PARTICIPATION IN COUNCIL

1. Do you feel that most families and friends are aware of the council and its purpose?
2. Is there a core group of families and friends that attends most meetings and offers help?
3. Is information about your council readily available to families who are new to the home?
4. Do you think most council members feel they can speak honestly at meetings?
5. Are council projects and tasks spread among members so no one person is overwhelmed?

IV. PROCESSING COUNCIL CONCERNS

1. Does the council focus on problems experienced by many families, rather than the problems of one individual?
2. Does the council have a system in place for processing family concerns?
3. Is this system effective?

V. COUNCIL ACTIVITIES

1. Are projects and programs varied enough to reflect the interest of different members?

2. Do all members feel they have had input into the selection of council projects?
3. Is the council involved in welcoming or orienting the families of new residents?
4. Is your council knowledgeable about the duties, functions, responsibilities of the various departments with the facility?
5. Has the council sponsored a special event or activity for families, residents or staff?

VI. NURSING HOME STAFF PARTICIPATION IN COUNCIL

1. Do you think most of the staff are aware of the council's existence and purpose?
2. Is information about the council included in staff orientation, trainings or meetings?
3. Has a staff liaison been chosen to work with the council?
4. Could the council continue to function at its current level if the staff liaison left?

VII. ADMINISTRATION PARTICIPATION IN THE COUNCIL

1. Do you feel the administration is supportive of the council?
2. Is there a system for informing the administration of council meetings and activities?
3. Does the administration keep the council informed of news and changes in policies and regulations?
4. Does the administration seek the council's opinion on policies, procedures and other issues regarding the nursing home?
5. Is the administration responsive to council concerns and recommendations?

VIII. SPECIAL 16 POINT BONUS QUESTION

Do you feel that the council has had a positive effect on families, residents and the home?

RESOURCES

Books

Advocacy Center for Long-Term Care, 2626 E. 82nd Street, Suite 220, Bloomington, MN 55425-1381, Tel. 612-854-7304

- *Attracting Short-Term Residents and Their Families to Resident and Family Councils.* (1997).
- *Discussion Topics To Stimulate Participation in Family Council Meetings.*
- *The Effective Council Advisor: A manual for advisors of resident and family councils in nursing and boarding care homes.* (1997).
- *Family Council Purpose.* (1997).
- *Failsafe Your Family Council* (1997)
- *Family Councils in Action: A manual for organizing and developing family councils in nursing and boarding care homes.* (1994).
- *Framing a Bill of Rights and Responsibilities for Residents' Families.* (1997).
- *Increasing Council Participation* (1997)
- *Making the Most of Cultural Diversity.* (1997).
- *Minnesota's Nursing Home Residents' Bill of Rights.* (1997, Jan.)
- *Promoting Your Family Council* (1997)
- *Recruiting Members for Your Family Council*
- *Team Building in Resident and Family Councils.* (1997).
- *What Do Family Councils Do?*
- *From the Family's Perspective: A training video to help staff understand the family's perspective and expectations while a loved one lives in a nursing home.* (1998).

Friends and Relatives of Institutionalized Aged (FRIA), 11 John St., Suite 601, New York, N.Y. 10038, Tel. 212-732-4455

- *Family and Friends Councils: Start-Up Packet.*
- *FRIA Bulletins: Family Councils.*

California Advocates for Nursing Home Reform (CANHR) 1610 Bush St., San Francisco, CA 94109, tel. 415-474-5171

- *Organizing Family Councils in Long Term Care Facilities.*

People

Patrice Carpenter

Regional LTC Ombudsman
Ark-Tex Area Agency on Aging
P.O. Box 5307
Texarkana, TX 75505
(903) 832-8636/(800) 372-4464
aaa@atcog.org

Virginia Cross

Advocates for Nursing Home Residents
9901 Satterfield Drive
Little Rock, AR 72205
(501) 225-4082
vacross@juno.com

Geoff Lieberman

Executive Director
Coalition of Institutionalized Aged
& Disabled (CIAD)
Brookdale Center on Aging
425 E. 25th Street, Room 818
New York, NY 10010
(212) 481-4348

Catherine Macomber

Regional LTC Ombudsman
Citizens for Better Care
6722 East Curtis #2
Bridgeport, MI 48722
(800) 284-0046

Gail MacInnes

Family Liaison

National Citizens' Coalition for Nursing Home Reform
1424 16th Street, NW, Suite 202
Washington, D.C. 20036-2211
(202) 332-2275

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