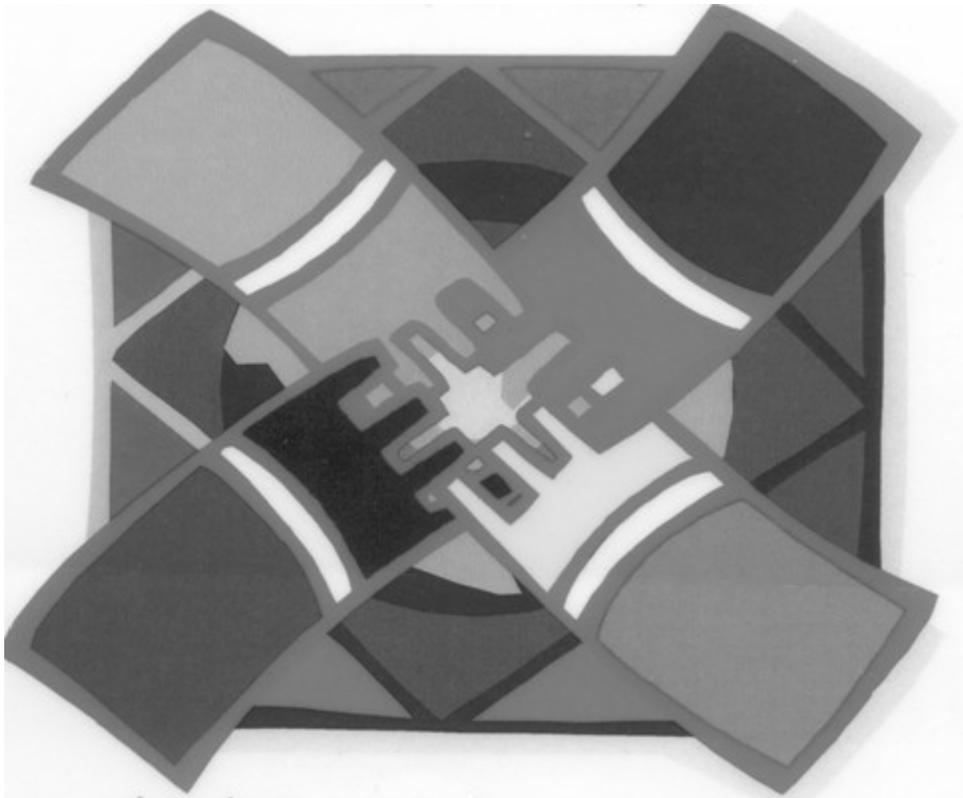


The How-To Why-To Guide to Smart, Strong Family Councils in Nursing Homes





What is a Family Council?

A family council is an organized, **self-led**, democratic group of family and friends of nursing home residents. A family council meets regularly to discuss **shared concerns** about the **quality of life** and **quality of care** of the residents in their home, and find **answers to shared problems**. All family councils promote communication, action, support, and education. What each council does depends upon the needs of the residents and the choices of the council members.

Just as schools have a parents' association, family councils are how family members can actively participate in improving the quality of care and quality of life of all residents of the nursing home.



The ICBC Family Council Project organizes, educates and supports family councils.



Why Spend Your Time on a Family Council ?

If you have a friend or relative in a nursing home, you know you are needed now more than ever before.

Most nursing home residents are physically or mentally unable to ensure their own quality care and dignity of life. Many are totally unable to speak up for themselves. The lucky ones have you -- their family and friends -- to speak for them.

But no matter how hard you try, you may find that, acting alone, you cannot get all you want for your individual resident.

Why not? Because, hard as you try, you can't see everything. Smart as you are, you can't know everything. And because, when you act alone, it can be all too easy to dismiss your concerns as exaggerated, or say they do not represent the experiences of other residents.

So why a family council? Because there is strength in numbers.

Other residents' family and friends can be there when you are not. They may see what you do not. They may have ideas you do not think of. **Together your voice has strength and authority you cannot command alone.**

FAMILY COUNCILS ARE THE BEST

- ◆ The best prevention against abuse and neglect
- ◆ The best way to persuade a facility of the need for a change in culture
- ◆ The best way to involve the community in the life of the home
- ◆ The best way to show ongoing appreciation for staff
- ◆ The best way to address systemic issues regarding changes in laws, regulations and policies that affect residents in facilities across the state and nation.



Steps to an Effective Family Council

1	<p>Interested family and friends come to the informational meeting.</p> <p>At the meeting, ICBC will explain what a family council is, what it does, and why it is important to have one in your facility. Everybody gets sample bylaws and mission statement. One person takes minutes. People may want to raise issues they want the family council to address. Even if the nursing home staff had helped to plan the meeting, they will not stay for the discussion.</p> <p>By the end of the meeting, the group should have agreed on a regular meeting time and place. Some people should volunteer to help plan the next meeting. Everyone at the meeting should be thinking of what they can do to make the family council a success.</p>
2	<p>After the informational meeting:</p> <ul style="list-style-type: none">◆ Post minutes on family council board, and give copies to the staff liaison.◆ Post meeting time for the first council meeting.◆ Contact family members. Ask the facility to send notice of the meeting in the next billing or newsletter.◆ Plan the first meeting. (ICBC will help).◆ Every family council member comes to the first council meeting with a list of issues (s)he wants the council to address, and at least one job (s)he is willing to do to make the family council a success.
3	<p>The First Family Council Meeting</p> <ul style="list-style-type: none">◆ Adopt a mission statement and bylaws.◆ Elect officers.◆ Everybody has a job.◆ Discuss issues members want the council to work on.◆ Form an Action Plan.◆ Choose the next meeting time and place.
4	<p>Keep up the good work. Don't miss any chance to publicize meetings and recruit members. Never forget your goal: to make life better for all residents. Congratulations! You have a Family Council!</p>



What the Nursing Home Must Do

<p>The 1987 Nursing Home Reform Law, and state Public Health rules, guarantee family and friends the right to form and hold regular meetings of a family council. They also say that:</p> <ul style="list-style-type: none">◆ The family council can meet where it chooses. If the council wants, it shall be given a private meeting room in the nursing home during mutually agreed upon hours.◆ The nursing home facility shall provide a designated staff person to provide assistance and answer written requests that result from family council meetings.◆ The nursing home shall listen to the views and act upon the grievances and recommendations of residents and families◆ Staff or visitors may attend family council meetings only at the group's invitation.◆ A home may not prohibit the formation of a family council when requested by a member of the resident's family or the resident's representative.◆ A home must make from the council or prospective council members, available to all current and prospective residents and their families or representatives.
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A Functional Family Council: Organization, Membership, and Action

There are 3 keys to a functional family council.



- ◆ A family council must be **organized**. People without direction, leadership, or structure cannot act effectively, or encourage others to join with them.
 - ◆ A family council must have **members**. It must keep its current members, and recruit new members to keep their group alive and functioning. The more family members that are involved, the greater number of voices that will be heard, and the stronger the group.
 - ◆ A family council must **act**. It may choose to have educational meetings for members or staff, sponsor resident activities, or ask the nursing home to address specific quality-of-care issues. The council is most likely to succeed if it has open lines of communication with the nursing home administration and staff. This does not mean that everybody always has to agree.
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Organization

Family council members are volunteers donating personal time to improve the quality of life of somebody they love. Their time must be used effectively and efficiently.

To stay organized and on track, a family council needs:

- ◆ A **mission statement** that describes the group and its purpose.
 - ◆ **Bylaws** that set the rules for meetings and how the group will operate.
 - ◆ An **agenda** that describes what is supposed to happen at each meeting. Sticking to the agenda will help members focus on their purpose. **The family council will succeed only if members work together to decide what they want and how to get it.**
 - ◆ **Minutes** taken by a member at every meeting, so that all members will know what happened at every meeting and what action the council decided to take.
 - ◆ A way council members can **share information**: a phone tree, e-mail, a council bulletin board in the nursing home.
 - ◆ An **action form** to express concerns to the administration and require a response.
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Membership

Although there may be a membership committee, **every council member should be involved with recruitment.**

To keep its current members, and get new ones, the family council can:

- ◆ Keep up a **family council bulletin board** with the next meeting time and place, mission statement, bylaws, contact information, minutes, and group successes.
 - ◆ **Post family council meeting information** where all visitors can read it.
 - ◆ If the facility has a newsletter, ask them to reserve a spot for council updates.
 - ◆ **Educate staff** about the family council, so that they can refer family members.
 - ◆ Use a **suggestion box**
 - ◆ Put a flyer or brochure in every facility mailing.
 - ◆ Set up a **welcome table** in the lobby to introduce the family council to visitors.
 - ◆ **Publicize** in local newspapers, church bulletins, or radio stations.
 - ◆ Personally **invite** family members: **council members should bring council information to share, every time they visit the home.**
 - ◆ Ask the admissions officer to include family council information in the **admissions packet**.
 - ◆ Arrange with the facility to send a **welcome letter** to new families from the family council.
 - ◆ **Sponsor activities** for all family members and residents.
 - ◆ Keep council meetings interesting, varied, respectful and meaningful to all members.
 - ◆ Build **council spirit**. Establish traditions, create a motto, hold a social event. Have fun with each other.
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Why do People Volunteer ?

- People volunteer if someone they love benefits from the organization's work.
- People volunteer when they have benefited themselves.
- People volunteer when they think their work will make a difference.
- **People volunteer when someone asks them to.**

Planning and Taking Action

The council will probably want to take on both short-term and long-term activities. A short-term activity can be achieved within a short amount of time: an educational or staff appreciation event, for example. A long-term activity may take a long time to achieve, or requires continual resolving: staffing concerns, for example.

To decide what to do, and how to do it:

- ◆ Identify concerns that affect many residents.
- ◆ Gather information. What needs to be done? Who will be involved, and when can they get to work? Why is this problem happening? How can the family council support proposed solutions?
- ◆ Talk over possible solutions.
- ◆ Consider how to document the existence of a problem.
- ◆ Formally present your concerns and solutions to the administrator and appropriate staff through the **council action form**.
- ◆ Allow enough time for the home to reply and act.
- ◆ Discuss the home's response. If it is satisfactory, tell the staff liaison. If it is not, file another **council action form**. Remember: **you can ask for help from ICBC or the Ombudsman program**.
- ◆ Tell residents, staff, and family members when and how the issue was resolved. Post your successes on the council bulletin board, in the facility newsletter, etc.
- ◆ Show appreciation when the home is responsive.

“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 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.”

-Maryland family council member

Keys to Success

- ◆ Meet with the administrator
- ◆ Involve facility staff
- ◆ Put it in writing!
- ◆ Pick your battles
- ◆ Do your homework
- ◆ Stick to the agenda
- ◆ Involve the residents
- ◆ Post bylaws and mission statement
- ◆ Recruit, recruit, recruit
- ◆ Develop method of communication with other families
- ◆ Communicate with all families
- ◆ Every member has a job
- ◆ The council has leadership
- ◆ Celebrate cultures of residents and staff

What About Individual Concerns?

The council should take all concerns seriously, but it will focus on those that affect many residents. The council should teach and empower families to be their own advocates.

Families should learn how to:

- ◆ Keep a log: date, time, shifts, places, staff members and residents involved in the complaints.
- ◆ Take concerns to administration and/or department heads as appropriate. Put them in writing.
- ◆ Raise concerns when they occur. Do not wait for council meetings.
- ◆ Attend and participate in care plan conferences.
- ◆ Know the residents' rights.
- ◆ Know about current best practices and examples of nursing homes providing individualized care.
- ◆ Know how to get help from the ombudsman and ICBC.



Obstacles and Conflict

Obstacle	Possible Solutions
Family members don't have time for council meetings and participation	<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 is not too great. • Use an agenda to keep meetings on track. • Schedule meetings at times that are most convenient for family members.
Family members aren't interested	<ul style="list-style-type: none"> • Introduce yourself to other family members on your loved one's unit. People will respond to a personal invitation more readily than to a letter or flyer. • Explain the importance of family councils to other family members and the potential that family councils have to improve residents' lives. • Introduce the concept of a family council in a positive way. Family councils can be useful for advocacy, 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, consider meeting someplace else -- a church, the library --so that family members will feel more comfortable coming to meetings. • Explain that family council members give each other support and strength. Also point out that issues or concerns will be presented to the administration as a group, not an individual concern. • Present the family council positively to both family members and nursing home staff.
Council members get discouraged easily	<ul style="list-style-type: none"> • Pick both short and long-term achievable goals so council members can see real progress. Make sure that council goals reflect their common concerns and interests. • Meet at least once every month to assure continuity and to make sure the council can identify current issues, set appropriate goals, and work to achieve them. • Publicize council successes, no matter how small. • Use community resources when stuck on a particular issue. Share ideas with family councils in other nursing homes.
Family members need information and education	<ul style="list-style-type: none"> • Contact ICBC if you have questions or need help. • Use the ombudsman, and other community programs, as resources. • Choose subjects council members want to learn more about, and arrange for speakers to come to a council meeting.
The family council experiences resistance from the nursing home	<ul style="list-style-type: none"> • Discuss and come to clear agreements with nursing home staff about what can be accomplished and expect that staff will follow through on those commitments. • Follow up on conversations with written communication to prevent misunderstandings. • Have a few leaders meet with nursing home management to introduce the council and its purpose in a positive manner. • Communicate constantly and respond positively to concerns the facility may have. • Know the rights guaranteed to family councils by federal regulations. • Get help from ICBC or the ombudsman.
The council has difficulty getting names of other family members	<ul style="list-style-type: none"> • See above suggestions on how to work with the facility • Start a "buddy system" where council members greet new families and invite them to council meetings. • Bring council information each time you visit, to give to possible new members. • Keep a sign-in sheet for each meeting and gather contact information.



Community Resources

Family Council Information & Support

Illinois Citizens for Better Care

100 West Monroe Street Suite 1800
Chicago, IL 60603
(312)663-5120
www.illinoiscares.org
Support, education and information for residents and family members; lobbying for residents and families on nursing home issues.

The National Consumer Voice for Quality Long-Term Care was formed as NCCNHR (National Citizens' Coalition for Nursing Home Reform)

1001 Connecticut Avenue, NW, Suite 425
Washington, DC 20036
202.332.2275
info@theconsumervoic.org (e-mail)
<http://www.theconsumervoic.org/>
Advocates for nursing home residents throughout the United States. Family council tips and tools.

California Advocates for Nursing Home Reform (CANHR)

1610 Bush St.
San Francisco, CA 94109
(415)474-5171
www.canhr.org
Advocates for nursing home residents through community education, legislation, and litigation. Free "Organizing Family Councils" booklet.

Family Councils Project

40 Orchard View Blvd., Suite 219
Toronto, Ontario, M4R 1B9
www.familycouncils.net
Website dedicated to family councils. Free comprehensive manual.

Ideas for Improving Residents' Quality of Life

Alzheimer's Association

National office
225 N. Michigan Ave., Fl. 17
Chicago, IL 60601-7633
(312) 335-8700
<http://www.alz.org/illinois/>
Provides educational materials and speakers.

Bernard Cobbins, Regional Ombudsman Chicago Department on Aging

(312)744-5957
<http://www.cbrx.il.gov/aging/default.htm>
Investigates nursing home complaints, provides support for family councils in Chicago.

Sally Petrone, Illinois State Ombudsman

(217)785-3143
Sally.Petrone@illinois.gov
Supervises ombudsman program throughout Illinois.

Illinois Assistive Technology Program

1 West Old State Capital Hill Plaza, Suite 100
Springfield, IL 62701
1-800-852-5110
www.iltech.org
Offers free workshops, to non-profits, on technology that increases independence for disabled people.

Illinois Department of Public Health

Nursing Home Hotline

1(800)252-4343
<http://www.idph.state.il.us/webapp/LTCApp/ltc.jsp>
Regulates and inspects nursing homes.

www.Medicare.gov

Click on "Resource Locator" and then "Nursing Homes" for violation, staffing and other quality information about a nursing home.

Pioneer Network

35 East Wacker Drive, Suite 850
Chicago, IL 60601
(312) 224-2574
www.pioneernetwork.net
Culture change resource



icbc

**401 S. LaSalle St.
Suite 1400
Chicago, IL 60605
(312) 663-5120
www.illinoiscares.org**