

FAMILY MATTERS

***A NEWSLETTER OF THE ILLINOIS FAMILY COUNCIL PROJECT
ILLINOIS CITIZENS FOR BETTER CARE***

FAMILY COUNCIL SHARE

Fairmont Care Family Council, Chicago

Thanks to Illinois Citizens for Better Care (ICBC), in June of 2006, a family council was started at the nursing home facility where my mother has lived for nearly three years. Starting and maintaining a family council is not easy. Recruiting family and friends of residents to participate can be both challenging and discouraging. In addition to the often heard "I'm too busy, I don't have time," there is skepticism that the family council can make any difference in improving the quality of care in the life of a loved one. As with most challenges, however, if one persists positive results begin to appear. At this particular facility, the family council members have increased from less than a handful to a core group of ten to twelve. Also, the group meets on a regular basis, once a month, on the third Saturday morning of the month.

In addition, the family council has met with the facility administrators on several occasions to voice our concerns (in addition to putting them in writing) and propose solutions. As a result, we have succeeded in having some of our proposals implemented. One example of this is the assignment of the same nurses and CNAs to the same residents. Prior to our urging, nursing staff were rotated between four teams every few days causing confusing among the residents. This change has resulted in the two-fold benefit of improving the quality of care as the staff has the opportunity to better know each resident individually, as well as increasing staff job satisfaction.

More recently, the family council has been working with administration on assuring that all staff wear their ID badges with their names clearly visible at all times. In addition to being disciplined, and at the suggestion of the family council, staff who forget their IDs at home are to wear a temporary stick on nametag for the day. We are also working with administration on other issues such as the hiring of more bilingual staff.

Continued on page 5

FAMILY COUNCIL TIPS & TOOLS

Topic #6—Non-emergency Problem Solving

The council will probably want to take on both short-term and long-term activities. To decide what to do, and how to do it:

1. Identify concerns that affect many residents.
2. Gather information. Why is this problem happening? Who will be involved? How can the family council support proposed solutions?
3. Discuss possible solutions, potential consequences, and a timeline for action.
4. Present your concerns and solutions to the administrator and appropriate staff in writing.
5. Use the chain of command. (Determine if the administrator wants you to start with a department head or the administrator.)

Director of Nursing or other Department Manager



Administrator



Owner/Corporate Board



Ombudsman/IDPH

6. Give the home time to reply and act.
7. Discuss the home's response. If it is satisfactory, tell the staff liaison. If not, write them another letter, or consider alternative strategies.
8. Don't let the issue drop.
9. When an issue is resolved, tell residents, staff, and family members when and how.
10. Show appreciation when the home is responsive.
11. Consider other strategies when the home stonewalls, or promises to act but does not.
12. Be diplomatic: establish credible and cooperative relationships with the staff and administration.

SPOTLIGHT ON: ONTARIO FAMILY COUNCIL PROGRAM

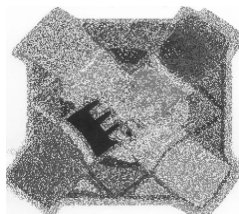
My trip to Ontario was enlightening — I saw physical proof that what family councils advocate for in Illinois is possible! Homes were clean and odor free, residents had a plethora of diverse activities to choose from, staff were not overwhelmed by the amount of residents to care for, and family councils were active and informed. Ontario is moving towards providing private rooms for all residents. As a result, many new homes have been built, providing smarter long-term care building designs. This page highlights Ontario best practices that could be implemented in Illinois.

ACTIVITIES:

- A different aide is assigned to each floor, supervising a unique set of activities. For example, if the home has 4 floors, there are 4 sets of activities going on at a time.
- Implementation of “virtual reality therapy” — interactive video games. The industry versions are expensive, so this nursing home purchased a Play Station system. Very popular with the residents. Check it out at <http://www.gameseek.co.uk/pd/PS2np4eh09m6147spt5/Eye-Toy-Play-2-+-Eye-Toy-Camera>
- Activities are announced in the morning and at noon.
- Alzheimer’s unit is decorated with furniture from when the residents were young.
- Every floor has its own activity room — separate from the dining and TV rooms.
- Every dining room has a white board that states all activities between this meal and next.
- Activity schedules for the month are posted (with copies) at the Activity Director’s office door; names of aides are also here, along with their floor assignment(s).
- Residents’ higher monthly allowance (IL=\$30) gives activities more options. One home had a sushi class for \$7.

DINING EXPERIENCE:

- Every dining room has a steam table. Food is brought here from the kitchen, and is then served onto plates to the residents.
- A small kitchenette (refrigerator, microwave, coffee maker) is available for capable residents (or family members).
- A color coded seating chart is tucked into the serving area, noting who can have what. This is especially beneficial for new CNAs, or those who rotate floors.
- A family room is available for when a resident celebrates a birthday, holidays, or if a family wants to have a meal with the resident. It really does look like my mother’s dining room, and the home will cater if requested.
- Kitchen staff serve food, while CNAs help residents eat.
- Family council helped install vending machines—15% of profit goes to the home.



FAMILY COUNCIL:

- Family councils engage in fundraising activities because the government subsidy is often insufficient.
- Chairperson Disclaimer: “It is my job to move the meeting along; if I interrupt you, it’s not because I don’t like you, it’s because we need to move forward.”
- Many family council members continue after their loved one dies, as a program facilitator.
- In order to work, there must be a process (suggestion box, grievance forms) - systemic change does not occur NOW
- When members get snippy, or being to gripe, ask: “why are we here?”

MISC.

- Administrators have a small bulletin board on their door where they post notices: resignations, new policies, etc.
- Every floor has its own cat.
- Residents usually do not change rooms. Many were decorated like at home—their curtains, bedspread, loveseat, rug, etc.
- All visitors are required to use hand sanitizer before entering: provided at the sign-in desk.
- Charge nurse on duty is posted.

The Ontario Family Council Program began in 1998, and uses over 15 volunteer facilitators to support over 450 family councils. In February, Alicia Loucks, Family Council Program Coordinator, attended their province-wide family council conference, and visited 3 long-term care homes. For more information about the Ontario Family Council Program, visit: www.familycouncils.net.

FEDERAL AND STATE POLICY UPDATES

ILLINOIS POLICY BRIEFING—PROPOSED LEGISLATION

- *HB3508 Aging—Long Term Care Ombudsman.* Requires nursing homes to file an annual Consumer Choice Information Report beginning July 1, 2008. Provides that a nursing home's violation of the law is an unlawful practice under the Consumer Fraud and Deceptive Business Practices Act.
- *HB0368 Public Aid—Personal Needs Allowance.* Provides that the minimum monthly personal needs allowance for a person who is an inpatient in an institution or facility for which payments are made under the Medical Assistance Article throughout a month, and who is determined to be eligible for medical assistance under that Article, is \$50.
- *HB1301 Long Term Care Ombudsman.* Allows the Long Term Care Ombudsman to communicate with, seek consent of, inspect records of, and do other things for nursing home residents, "regardless of [the resident's] age". Effective immediately. **Contact your legislator with your support for this bill.**
- *SB0322 Medicaid—Nursing Home Pay Increase.* Provides for an increase in Medicaid rates for nursing homes for the sole purpose of increasing wages or providing new or enhanced employee benefits for non-supervisory employees. Requires nursing homes to apply for the rate increase. Effective immediately.

To view current bill status, visit the Illinois General Assembly at www.ilga.gov/legislation/default.asp
 For tips on how to contact your legislator, visit Illinois Citizens for Better Care at www.illinoiscares.org/advocate.html

FEDERAL POLICY UPDATE—ELDER JUSTICE ACT

The campaign has begun to pass the Elder Justice Act in 2007! Your help is needed! In past years, the bill came close to passing but failed because of lack of support in the House of Representatives. It is extremely important to get members of the House to co-sponsor and support the bill this year. **Please contact your U.S. Representative's office and ask for him or her to co-sponsor the Elder Justice Act, HR1783.**

Ask them to support this bill because:

- Abuse and neglect of the elderly in long-term care settings are serious problems. (If you can, give a local example that shows this.)
- Long-term care ombudsmen across the country receive over 16,000 complaints a year about abuse, gross neglect, and exploitation. (Substitute a statistic from your state or area that shows the amount of abuse or neglect in your local facilities.)
- The Elder Justice Act will help public agencies combat abuse against all elderly. It is the strongest legislation introduced to protect nursing home residents in the past 20 years.

A number of provisions in the Act are directly related to protecting residents in nursing homes and/or other long-term care facilities. These would:

- Improve forensic investigation of elder abuse;
- Require number of adjudicated criminal violations to be published on Nursing Home Compare;
- Authorize new funding to improve ombudsman capacity and training;
- Authorize a national training institute for long-term care surveyors;
- Require operators and employees of any long-term care facility that receives federal funds to report "any reasonable suspicion of a crime" to law enforcement; establish fines for those who fail to report and protection from retaliation for those who do;
- Authorize a study on establishing a national nurse aide registry.

HR 1783 and the companion Senate bill, S. 1710, have not been posted on the Library of Congress website. When available, they will be at <http://thomas.loc.gov>. The House sponsors of the Elder Justice Act are Rep. Rahm Emanuel (D-IL) and Peter King (R-NY).

Questions? E-mail Janet Wells at NCCNHR, jwells@nccnhr.org, or call 202-332-2573.

PROGRAM UPDATES

The **Illinois Family Council Coalition (IFCC)** had its third meeting April 18, 2007 in Springfield. The IFCC is a group of family council members, citizen advocates, and ombudsmen, that: (1) to enable and promote communication among Illinois family council members; (2) to influence public policy related to long-term care; (3) to help family councils inform themselves about state-wide nursing home issues. Join the IL Family Council listserv to review the minutes. We are seeking more membership from west and north Illinois.

For more information, contact Alicia Loucks, (312) 663-5120, icbc@core.com

ICBC partnered with NCCNHR to produce the second **Family Council Education Conference Call**, February 27, 2007, on "Nursing Home Staff Roles: What They Are and What They Mean For Family Members." It featured Gale Arrieta, Director of Nursing at St. Francis Nursing and Rehab Center, Evanston, Illinois. Notes from this call can be viewed through the IL Family Council Listserv.

ICBC hosted the first **Chicago Family Council Leaders Luncheon** April 21, 2007. Keynote speaker was Rose Hilger, Nursing Home Resident Advocate. 31 Family Council Leaders and Staff Liaisons were honored for their commitment to bettering the quality of care and life of nursing home residents.

The **IL Family Council Listserv** is an electronic forum for family members of nursing home residents, citizen advocates, and ombudsmen to learn from one another. ICBC regularly posts articles and information about regional workshops of interest. Family members are encouraged to share their experiences, questions, and family council best practices. To sign up, email Illinois-Family-Councils@googlegroups.com or visit <http://groups-beta.google.com/group/Illinois-Family-Councils>

Family Council Project News

Funding for the ICBC Family Council Project has ended. We have applied for a grant from the Retirement Research Foundation to continue the project; RRF will make its decision in May.

Here's what this means for family councils:

ICBC remains committed to supporting family councils throughout Illinois. No matter what happens with future funding, we will still have a newsletter, support the Illinois Family Council Coalition, staff the listserv, and support the family councils that are already organized in Illinois. And we will continue to work with NCCNHR.

To the extent we are able, we will help family members organize new councils, especially in the Chicago area. We will not be able to try to start any new councils by ourselves, however, and may not be able to have family council member phone conferences, without funding.

Resources:

- [The 36 Hour Day: A Family Guide to Caring For Persons With Alzheimer Disease...](#), Nancy Mace & Peter Rabins
- Alzheimer's Association, Greater Illinois: www.alzheimers-illinois.org/
- Coalition of Limited English Speaking Elderly: <http://www.clese.org/>
- Illinois Citizens For Better Care: www.illinoiscares.org
- Illinois Family Council Listserv: groups.google.com/group/Illinois-Family-Councils
- Illinois General Assembly: www.ilga.gov/legislation/default.asp
- NCCNHR: www.nccnhr.org
- Nursing Home Regulations Plus: www.hpm.umn.edu/nhregsPlus/
- Ontario Family Council Program: www.familycouncils.net

The Chicago Family Council Project is a project of Illinois Citizens for Better Care. For more information, contact ICBC, 220 South State Street, Suite 1928, Chicago, IL, 60604, (312) 663-5120, icbc@core.com, www.illinoiscares.org

Continued from page 1

Furthermore, because the family council recognizes that it is also very important to acknowledge those things that are working well, the council has plans to show its appreciation to staff by putting in place some form of recognition from the family council—a certificate, a letter—recognizing outstanding staff.

In participating in a family council, I have learned that others are struggling with the same things in dealing with nursing home issues as my mother, my family, and I have been facing. Also, I have been reminded that, as the ICBC brochure titled *The How-To Why-To Guide to Smart, Strong Family Councils in Nursing Homes* states, “[t]ogether [our] voices have strength and authority [we] cannot command alone.” Moreover, I have seen that having a family council in a nursing facility definitely makes a difference in the quality of care and dignity of life of residents.

Family councils exist to find answers to the shared concerns of everyone in the facility, in doing so, however, they impact individuals because what benefits one benefits all, even if only peripherally. I find it rewarding to know that I am part of a group that is actively working to ensure the best care possible for all the nursing home residents at the facility where my mother resides. But, in addition, it gives me some peace of mind to know that my mother is more likely to be treated with dignity and receive the quality care she deserves as a result of having a family council in place at the facility.

Maria G. Acosta, Family Council Leader

FAMILY COUNCIL LEADERS LUNCHEON



Willa Martin and Sonya Clyborn
(Renaissance at 87th Street)



Jeannette and Glenda Lewis
(Halsted Terrace)