

# ***FAMILY MATTERS***

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

## **FAMILY COUNCIL SHARE**

### ***Heritage Manor Family Council, Chillicothe, Peoria County***

A family council formed at Heritage Manor Chillicothe in 2003 at the request of the ombudsman with open support from the facility management.

Our first accomplishments included a process for communicating to families, brochure for distribution in admission packets, bulletin board to use as a communication tool, monthly meeting where families share issues, direct line of communication with the administrator, and reasonable CNA rotation.

The creation of the Shining Star Board is a positive avenue to recognize and thank others. It is a simple cork bulletin board hanging in the main hallway. Special star paper is available at the board for writing notes. Our original intent was to use the bulletin board to thank employees who care for our loved ones, but employees use this board to thank each other!

The nursing home started a gift shop where residents pay a quarter to enter and leave with two items of choice. We provided quarters to fund the entry fee and stocked preferred items that residents wanted in the gift shop.

We constructed a wheel of appreciation, gathered prizes, and documented a process for using the wheel to recognize "above and beyond" actions of the employees. We created a maintenance request form, built a collection box for the maintenance requests, and documented a process for using it. We started a garden club where residents enjoy taking cuttings from geraniums, watching them root, and then planting them in the flower gardens. We assist with the annual Alzheimer's River Valley Memory Walk, and upon request, in the beauty shop.

Sustaining a successful family council demands the efforts of families and friends getting involved and working together. In an effort to encourage participation, we have sponsored the Father's Day Breakfast, Coffee with Friends, Hanging of the Greens, and flower planting & clean up of the flower gardens.

In January 2007, Heritage Manor achieved the first ever deficiency-free Public Health survey in Chillicothe, which is a direct reflection of the entire Heritage team working together. The family council is proud to be included in this team.

Vicki Okerberg, Family Council Leader

## **UPCOMING EVENTS**

July 16: Illinois Family Council Coalition (IFCC) Location TBA. The IFCC is a coalition of family council members from throughout Illinois that:

- (1) enables and promotes communication among Illinois family council members;
- (2) influences public policy related to long-term care;
- (3) helps family councils inform themselves about state-wide nursing home issues.

July 26: Family Council Education Conference Call #3 — Effective Care Plan Meetings 7:00-8:00 PM  
Call 312.730.8370 to register. *Space is limited.*

August 2: Family Council Wine & Cheese Open House 5:30-7:30 PM  
Park National Bank, 801 N. Clark St., Chicago  
*Limited Free Parking Available*

Come to:

- Network with other family council members;
- Hear about other family council success stories;
- Learn how to start a family council.

For more information, call Alicia Loucks at 312.730.8370, or email [aliciaicbc@core.com](mailto:aliciaicbc@core.com).

## BASIC INFORMATION ABOUT "SURVEYS"

Every nursing home in Illinois that accepts Medicare or Medicaid payment, must be inspected by the Illinois Dept of Public Health at least once a year. Other Illinois nursing homes must be inspected annually if they have a recent history of serious violations; otherwise, they are inspected only once every 2 years. In addition to these (mostly) annual inspections, Public Health is required to investigate on-site when it gets a complaint that says the facility has violated state or federal nursing home requirements. Public Health sometimes also inspects when it gets information from a nursing home — they call them "incident reports" — that something happened that the state should know about. If the inspectors find serious violations of state or federal requirements on any visit, they are required to keep coming back until the violations are gone.

All these inspections are called "surveys." The inspectors are "surveyors." The written results of the inspection are usually called "survey findings," or, sometimes, just "surveys." Every nursing home in Illinois is required to keep the past 5 years of surveys, and all related correspondence (notices of fines and other penalties, appeals, penalty reductions) available to **any member of the public** who wants to see them. The material is usually kept either at the front desk or the administrator's office.

**Who are the surveyors?** Most of them are nurses. Public Health also has "sanitarians," who are trained to look at issues of food handling and safety and other cleanliness-related issues, and to see if residents' rights are being protected. There are also a few architects, who check for compliance with building code and other safety requirements related to the building and building maintenance.

**What gets looked at during a survey?** The issue during the **annual** survey is whether the nursing home is meeting all state and federal requirements. Unfortunately, **this does not mean that the surveyors check the care being given to every resident:** there are not enough surveyors to do this. Instead, before they get to the nursing home, the surveyors see information about the health status and care of every resident, recorded in the individual's Minimum Data Set (the "MDS"), and sent by the home to the Public Health computer. They use the MDS information to choose a small number of residents whose care they are supposed to examine in depth. The sample is mostly high-risk residents: those who are reported to have been restrained, lost a lot of weight, or developed pressure sores, for example. While the surveyors will look at other residents, especially when watching mealtime in a dining room, or medication being passed, they are supposed to spend much of their time on the sample residents. They are also supposed to interview residents, and some family members. Although there will be signs in the facility saying that the surveyors are there, family members who try to discuss care-related issues commonly report that surveyors refuse to look into the information, instead telling them to call the Public Health hotline (1-800-252-4343.)

Sometimes the annual survey will also include one or more complaint investigations. This is because, although Public Health has only 24 hours to investigate a complaint if a resident is in immediate danger, it is allowed to take from 7 to 30 days to investigate other complaints, depending on how serious they are. This allows Public Health to consolidate multiple complaint investigations, or to join them with an annual survey.

A complaint investigation is much more focused than is an annual survey. Surveyors look only at issues raised by the complaint: they don't look around the place, observe mealtime, medication being passed, or infection control techniques unless somebody has complained about them. They do attempt to protect the identity of the resident(s) about whom a complaint was filed, by examining the records and care of additional residents. If they are investigating a complaint about one resident in an Alzheimer's unit, for example, they will check on 3 residents in the unit.

The surveyors don't make the final decision about whether a facility is cited for violations after a survey. Their recommended findings go through a quality control unit, and sometimes are reviewed by a Public Health lawyer.

**Next time:** "How To Read a Survey"

## STATE AND FEDERAL POLICY UPDATES

### ILLINOIS POLICY BRIEFING—2007 LEGISLATION

- **Long Term Care Ombudsman:** HB1301 — ICBC's bill — has now passed both houses of the Legislature. If it is signed by the Governor, it will allow ombudsmen to represent all residents of nursing homes and assisted and supportive living facilities, instead of just residents who are at least 60 years old. It will also require the Department on Aging to provide training for ombudsmen to help them represent such "special needs" populations as children, and persons with developmental disabilities and mental illness. We expect that inadequate funding will mean many of the 16 ombudsman programs will restrict their representation of younger residents, or refuse to do so altogether.
- **Nursing Home Information website:** This bill to require nursing homes to fill out a questionnaire about their services, the results of which would be on the Illinois Dept of Aging website, was HB3508. That bill is dead; the text has been put into SB0866. The deadline for passage is the end of 2007.
- **Personal Needs Allowance increase:** There are a number of bills increasing the monthly personal needs allowance of residents on Medicaid, from \$30 to either \$50 or \$90. Whether this happens, and how (one bill increases it \$5 / year over 4 years) depends on the final budget negotiations, and whether enough legislators make it a priority.
- **Pay Increase for non-supervisory nursing home employees:** The fate of SB0322 also depends on the final budget negotiations.

To view current bill status, visit the Illinois General Assembly at [www.ilga.gov/legislation/default.asp](http://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](http://www.illinoiscares.org/advocate.html)

### FEDERAL POLICY UPDATE

#### **Elder Justice Act Gains More Co-Sponsors**

The Senate Elder Justice bill (S. 1070) now has nine Senate co-sponsors, and the House bill (H.R. 1783) is up to 61. To see whether your senators and representatives have signed up, check Bill Summary and Status on Thomas, <http://thomas.loc.gov>.

#### **Fire Safety Legislation Reintroduced in the House and Senate**

Rep. John Larson (D-CT) and Rep. Peter King (R-NY) have reintroduced the *Nursing Home Fire Safety Act* (H.R. 2521), a bill that would provide loans and, in cases of hardship, grants to nursing homes to retrofit their buildings with automatic sprinkler systems. Senator Christopher Dodd (D-CT) and Senator Richard Burr (R-NC) have introduced a companion bill, S. 1615. Both bills include a nonbinding "sense of the Congress" that within five years, every nursing home should be equipped with sprinklers. NCCNHR endorsed the Larson-King bill last year but has not yet taken a position on H.R. 2521, which "in unique circumstances" would allow some facilities to use remedial actions other than complete sprinkler systems if they did not have an adequate structure to retrofit the entire facility. S. 1615 does not contain this exemption. You can access the bills at <http://thomas.loc.gov>.

#### **Senate Bill Would Exempt All Dually Eligible Long-Term Care Residents from Drug Co-Pays**

Senator Gordon Smith (R-OR), ranking Republican on the Senate Special Committee on Aging, has reintroduced a bill that would implement NCCNHR members' 2006 resolution asking Congress to exempt all long-term care residents who are eligible for both Medicare and Medicaid from Medicare Part D drug co-pays. (See resolutions on the NCCNHR website, 1986-2006.) The *Home and Community-Based Services Copayment Equity Act*, S. 1107, would give dual-eligible residents in assisted living, board and care, and other residential care settings the same exemption from Part D co-payments that nursing home residents receive. State-licensed mental health facilities would also be covered. The bill is posted at <http://thomas.loc.gov>. There is currently no House bill.

Questions? E-mail Janet Wells at NCCNHR, [jwells@nccnhr.org](mailto:jwells@nccnhr.org), or call 202-332-2573.

## **FAMILY COUNCIL TIPS & TOOLS: Topic #7—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!

### **I. ESTABLISH GROUND RULES**

- 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, 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;
- Discuss one topic at a time;
- Use facts, not assumptions.

### **II. USE COMMITTEES**

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. Families may feel less intimidated if you simply ask 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. Use this to move forward on an issue; for example, if a member consistently notes a lack of Spanish-speaking staff, ask them to meet with the appropriate administration and report back to the council. If they are unwilling to do this, note that it is not a council priority, and will be dropped from the discussion.

### **III. PREPARE FOR THE MEETING**

- Review the minutes from the previous meeting to remember 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 — when most people will be present;
- Include time for concerns to be raised/discussed;
- End on a positive note;
- Distribute the agenda at least one week prior to the meeting: post it at the nursing home, e/mail it to members, have copies available to pick up at the home.

### **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 number and e-mail addresses;
- Start on time;
- Post ground rules during meetings;
- Introduce meeting participants, especially those attending for the very first time;
- Be firm about sticking to the agenda. When members raise issues not on the agenda and there is not time for discussion, ask them if they would like it to be discussed at the next meeting;
- Be firm about time frames without cutting off good discussion. If an item takes longer than planned, members can vote to continue and postpone other agenda items;
- Ask for the opinion of silent or less active members;
- Periodically summarize what has been said and ask for additional input;
- 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 steps needed; determine who is responsible for each step and time frames for those actions;
- When tasks are identified that need to be done, ask for volunteers.

Adapted from "Family Guide to Effective Family Councils," Robyn Grant, The Legal Assistance Foundation of Metropolitan Chicago and the Evanston Commission on Aging, 111. W. Jackson Boulevard, 3rd Floor, Chicago, IL 60604.

## HOT TOPIC: COPING WITH STROKE

When a loved one has a stroke there are many adjustments that the family needs to make in order to deal with the physical and emotional difficulties that can arise. After a stroke many daily activities such as walking, talking, and writing may seem too difficult for a stroke survivor to handle. Feelings of anger and guilt may overwhelm a caregiver which creates the need for peer support, hope, and encouragement. Joining or creating a stroke survivor or caregiver support group allows you to find individuals in similar situations that you can share concerns and support. *Source: Adapted from American Stroke Association "Family Caregiver Alliance: Dementia, Caregiving and Controlling Frustration." and the Stroke Network Stroke Caregivers Handbook*

### Illinois Stroke Resources

Aphasia Conversation Group and Classes  
Rehabilitation Institute of Chicago (RIC)  
Meets weekly on Tuesdays and Thursdays  
Contact: Dr. Leora Cherney or Edie Babbitt  
(312) 238-6163.

Stroke Prevention Program  
Northwestern Memorial Hospital, Feinberg Pavilion  
Chicago  
For information go to <http://www.nmh.org/> or call  
(312) 926-8400.

Stroke and Head Injury Support Group  
Herrin Hospital Conference Room 1A Herrin  
1st Thursday of each month at 2 p.m.  
Contact: Lisa Melton, (618) 942-2171 ext. 35312.

Community Stroke Support Group  
Regional Rehab Center of Memorial Medical Center -  
Springfield  
Held every 2nd Saturday of the month at 1:00 p.m.  
Contact: Lisa Cline (217) 788-3461 or email  
[cline.lisa@mhsil.com](mailto:cline.lisa@mhsil.com)

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](mailto:Illinois-Family-Councils@googlegroups.com) or visit <http://groups-beta.google.com/group/Illinois-Family-Councils>

### **Welcome New Family Councils!**

2 new family councils have formed since our last newsletter:

Winchester House (Lake County)

Breese Nursing Home (Clinton County)

Please check ICBC's website to ensure that your family council's most current info is listed.

[www.illinoiscares.org/fc\\_links/info\\_about09.php](http://www.illinoiscares.org/fc_links/info_about09.php)

### **Resources:**

- American Stroke Association:  
[www.strokeassociation.org](http://www.strokeassociation.org)
- Family Caregiving 101:  
[www.familycaregiving101.org/](http://www.familycaregiving101.org/)
- Family Caregiver Alliance:  
[www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp)
- Illinois Citizens For Better Care:  
[www.illinoiscares.org](http://www.illinoiscares.org)
- Illinois Family Council Listserv:  
[groups.google.com/group/Illinois-Family-Councils](http://groups.google.com/group/Illinois-Family-Councils)
- Illinois General Assembly:  
[www.ilga.gov/legislation/default.asp](http://www.ilga.gov/legislation/default.asp)
- NCCNHR:  
[www.nccnhr.org](http://www.nccnhr.org)
- National Family Caregivers Association:  
[www.nfcacares.org/](http://www.nfcacares.org/)

The Illinois 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](mailto:icbc@core.com), [www.illinoiscares.org](http://www.illinoiscares.org)