

# FAMILY MATTERS

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

## FAMILY COUNCIL TIPS & TOOLS

### *Topic #2 - Making Meetings Meaningful*

#### 1. Use Structure

- Agenda. Always have one, even if it contains just a few simple items.
- Meeting Length. If at all possible, try to limit the length of meetings to 1 hour, or 1.5 hrs.
- Regular meeting time. Try setting a regular meeting time (for example, meeting on the 3rd Thursday of each month) so that family members can plan ahead to attend Family Council meetings.
- Meeting Procedures. Try using agreed upon structure to keep meetings moving in an orderly and efficient manner.
- Input & Setting Group Goals. Family members must feel that they have input into group decisions, and that council activities will have an impact on the care their loved one receives. The council should schedule time for family members to have discussion and brainstorm without facility staff present.

#### 2. Structure for Discussion.

- Use a flip chart to compile lists of shared concerns and interests.
- Appoint a time keeper to remind the group to move on if discussion gets stuck.
- Hand out index cards and ask people to list top three areas of concern or interest. Then compile a group list.
- Use an egg timer to remind the group when it is the next person's turn to speak.

#### 3. Focus on Action and Efficiency

- Formulate Solutions & Recommendations. Brainstorm for solutions to concerns raised. Formulate a specific request for how a concern should be addressed.
- Next Steps. Before the end of each meeting always plot out next steps, review action items, and delegate tasks to be accomplished before the next meeting.

## IL FAMILY COUNCIL SUCCESSES

### Family Councils HAVE made a difference! Family Councils in IL have:

- Advocated for family members and responsible parties to have access to complete medical records at all times.
- Decreased sodium intake in residents' diets by requesting the dietary department to agree to wash canned vegetables in fresh water before cooking them.
- Compiled documentation, to be presented to the DON, of when they have found their loved one wet.
- Decreased call-offs by advocating that CNAs bid on their work schedules by seniority. A CNA who calls off must work the following weekend, if needed, or will be written up.
- Worked with administration to have a Family Council bulletin board in the main lobby. This helps new members get Family Council information.
- Advocated to add a 2nd snack cart in the evening because the Family Council said that with only one cart, many residents in one wing were asleep before the cart got to them.
- Advocated successfully for residents to be able to have food heated up whenever they wanted at night.
- Sponsored a "Happy Hour" on a Friday evening. Residents, staff, and family members enjoyed singing, karaoke, table games, ice cream, and finger foods. They plan to have it again.

### WHAT'S YOUR FAMILY COUNCIL BEEN UP TO?

To share your success stories in the next newsletter please contact Alicia Loucks,  
Family Council Program Coordinator:  
312-730-8370, [aliciaicbc@core.com](mailto:aliciaicbc@core.com)

## HOT TOPIC

### RESIDENTS' RIGHTS WEEK – CARE MATTERS: “CHOICE, ACCOUNTABILITY, RIGHTS, EMPOWERMENT”

The first full week of October (October 1-7, 2006) is Residents' Rights Week, designated by the National Citizens' Coalition for Nursing Home Reform (NCCNHR). Each year this is an opportunity to honor residents living in all long-term care facilities, in addition to honoring ombudsmen, citizen advocates, facility staff, and family members who work to respect residents' rights. Finally, Residents' Rights Week is a time to reflect on the importance of the *Nursing Home Reform Law of 1987* which promises each resident quality of life and quality of care and guarantees specific residents' rights.

#### PERSONAL NEEDS ALLOWANCE IN IL

The ombudsmen in Illinois are celebrating Residents' Rights week by circulating a petition to raise the Personal Needs Allowance (PNA) to \$90. The petition will be given to the legislature. Residents need a PNA to fulfill varied personal needs such as clothing, individual preferences on personal care items, social support, and occasional outings. The PNA affects the quality of life for the majority of residents in nursing homes. While the amount of PNA varies by state, the national average PNA is \$47.35.

For more information on the IL Ombudsman effort, or for a petition, contact your local ombudsman or the state ombudsman, Sally Petrone: 217-785-3143.



#### RESIDENTS' RIGHTS WEEK

##### ACTIVITY IDEAS AND SUGGESTIONS

- The family or resident council can work with the facility activity staff to organize an event honoring residents.
- Invite local dignitaries, and other community "celebrities," to a kick-off event and for a tour of the facility.
- Order a Residents' Rights week packet from NCCNHR. Share the materials in this packet with others.
- Have family members, residents, or staff submit "letters to the editor" in a community publication to share what Residents' Rights Week is about. Include what your facility is doing to recognize the week.
- Conduct a facility-wide poetry or story challenge.
- Participate in the NCCNHR Poetry Contest
- Design a Residents' Rights Week 2006 Bulletin Board.
- Arrange staff in-services on residents' rights and related topics.

**You can get information and ideas on creating events in your facility by contacting NCCNHR: 202-332-2275**

**For information on NCCNHR Residents' Rights Poetry Contest:**  
<http://www.nccnhr.org/uploads/RResayContestflyer.pdf>

## FEDERAL AND STATE POLICY UPDATES

### ILLINOIS POLICY BRIEFING

#### **PROPOSED RULE WILL STRENGTHEN FAMILY COUNCILS**

The Illinois Department of Public Health (IDPH) is going to propose a rule that will strengthen the ability of Family Council members to communicate with each other, and will help support ongoing Family Councils to reach current and potential members.

IDPH agreed to propose the rule after the Long Term Care Facilities Advisory Board began to hold public hearings at which family members testified about their difficulties in obtaining good (or even adequate) nursing home care for their relatives. Many of them said that they felt alone in their struggles, and had no idea where they could go for help.

The advisory board thought that strong Family Councils could give families support and negotiating power that neither Public Health nor the ombudsman can provide. After more than a year of negotiation, IDPH agreed to propose a rule that should fix what ICBC believes is the most important defect in the federal rules protecting Family Councils: that people who wish to form a council have no way to find each other, and that a council has no way to tell prospective members (including relatives of new residents) about the council.

The proposed rule will include a requirement that whenever requested by a Family Council, prospective council members, or the ombudsman, every nursing home must give information about the council. This information will have previously been submitted by the council. As with the federal rule, the facility would also have to arrange for a meeting place for the council. The rule would apply to all Illinois nursing homes, including facilities for the developmentally disabled and sheltered care facilities.

IDPH is expected to propose the new rule in the next few months. The Illinois Citizens for Better Care (ICBC) will have information on the website ([www.illinoiscares.org](http://www.illinoiscares.org)) about how to find the exact language of the proposed rule, and how to file a comment. It is important that people, who think the rule is a good idea, or those who think it could be improved in some way, contact IDPH. While some nursing homes are ok with the proposed rule, some are not. It is important that IDPH hear from people who support what they are proposing.

### FEDERAL POLICY BRIEFING

#### **THE NEW CMS MEDICAID PROOF OF CITIZENSHIP REQUIREMENT & YOU**

On July 12, 2006, the Department of Health and Human Services in Washington DC published the final regulations on citizenship guidelines for Medicaid eligibility. These are effective immediately. As of July 1, 2006, all people who get Medicaid or people who apply for Medicaid MUST be able to document that they are US citizens or nationals.

However, it is expected that only a few nursing home residents will actually be affected by the law. The Centers for Medicare and Medicaid Services (CMS) have said that if you are enrolled in Medicare or receive Supplemental Security Income (SSI), or are a "Qualified Alien," you will NOT be affected by this new law. Seniors and people with a disability, who receive Medicare or Supplemental Security Income, have already met certain documentation requirements. Therefore, this new regulation does not require these groups to further prove their citizenship. If you are already enrolled in Medicaid you will remain eligible if you continuously show that you are making a good faith effort to present satisfactory evidence of citizenship and identity.

If you still have questions, contact Medicaid: 1-800-MEDICARE (1-800-633-4227.) Or check the website: [www.cms.hhs.gov](http://www.cms.hhs.gov)

## EVENTS AND UPDATES

### THE 2<sup>ND</sup> ANNUAL FAMILY COUNCIL COALITION CONFERENCE *HAND-IN-HAND: QUALITY CARE & CITIZEN INVOLVEMENT IN NURSING HOMES* September 7-8, 2006 in Springfield, IL

You are welcome to attend this free conference including sessions on: Family Council Challenges & Successes; Filing a Complaint in IL; Advocating; Culture Change; and updates on new regulations and family involvement in the survey process.

For information on registration and events, contact Grace Sweatt: 217-523-8419, [grace@icare.ws](mailto:grace@icare.ws)

#### **VOICE TO QUALITY – EDUCATIONAL CONFERENCE CALL SERIES**

Residents and family members are invited to participate in NCCNHR's 2006 National Educational Conference-Call series, "Giving Voice to Quality." Previous calls highlighted issues related to restraint use in facilities and quality care planning. Information on upcoming conference calls, participant registration forms, useful tools and materials related to the series are available on the web: [www.nccnhr.org/consumervoice](http://www.nccnhr.org/consumervoice). Or contact: 202-332-2275, [voice@nccnhr.org](mailto:voice@nccnhr.org)

**You need to register to participate in this FREE educational call.**

#### **NATIONAL CITIZENS' COALITION FOR NURSING HOME REFORM 31<sup>ST</sup> NATIONAL CONFERENCE AND ANNUAL MEETING: *CARE MATTERS* October 22-24, 2006**

**at the Hilton Crystal City in Arlington, VA**

The conference will include: nationally recognized experts in the field of long-term care, in-depth and interactive sessions and workshops, networking opportunities, and more. Everyone concerned about quality long-term care and quality of life is welcome to attend. ***Scholarships are available.***

Registration Form & Fees available at:  
[http://nursinghomeaction.org/public/50\\_158\\_436.CFM](http://nursinghomeaction.org/public/50_158_436.CFM)

## RESOURCES

- **Illinois Citizens for Better Care (ICBC)** – [www.illinoiscares.org](http://www.illinoiscares.org) – This is the Illinois nursing home residents' advocacy and service organization.
- **Fact Sheets** – [http://www.nccnhr.org/public/50\\_156\\_434.CFM](http://www.nccnhr.org/public/50_156_434.CFM) – NCCNHR provides fact sheets on a variety of topics related to long term care; available on the web or, by request, in the mail.
- **ICBC listserv** – Sign up or learn more about the listserv. Email [aliciaicbc@core.com](mailto:aliciaicbc@core.com) or visit: <http://groups.google.com/group/Illinois-Family-Councils> – Use this excellent tool designed for family members who are part of Family Councils, or who are interested in starting one.
- **Long-term care cost reports** – <http://www.hfs.illinois.gov/costreports/> – These reports are available through the IL department of healthcare and family services on their website.
- **ElderCare Alliance** – [www.eldercarerights.org](http://www.eldercarerights.org) – This organization advocates for quality and assists people in securing needed care. They promote nursing home Residents' Rights, and provide guidance to family and friend caregivers seeking knowledge about rights, responsibilities, and resources within the long-term care system.

*The Chicago Family Council Project is a project of Illinois Citizens for Better Care, and the National Citizens' Coalition for Nursing Home Reform. For info contact ICBC, 220 South State St., Suite 1928, Chicago, IL 60604, tel. 312-663-5120.*