Family Councils: The Necessary Connection

During the 4th quarterly training, family councils were a major subject of discussion. Under the 1987 Nursing Home Reform Act:

- A resident’s family has the right to meet in the facility with the families of other residents.
- The facility must provide a family group with private space if a group exists.
- 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.

While laws and policies are generally helpful, bringing these councils into reality and making them work can be, at first, an uphill battle. Mostly due to the difficulty of engaging the facility and then the family members. That is, until the functionality of the family council is taught or otherwise becomes evident.

Here are some tips to successful use of family councils:

- Engage and educate facility staff.
- Ensure location of meeting is visible by family members.
- Involve family members committed to the council’s purpose.
- Create a newsletter telling meeting schedule.
- Keep the council going through its successes.

Family councils can play a crucial role in voicing concerns, requesting improvements, supporting new family members and residents. Family councils also assist the facility with efforts to strive for high quality of care and life for the residents. If all facilities had functional family councils, the culture of care would change, for the better in the residents favor.

Keeping the family connected has proven necessary and key to resident overall well being.

More information can be found at the National Ombudsman resource center online at: http://www.ltcombudsman.org/issues/resident-and-family-councils.

Notable quote-

“Long Term Care Ombudsman don't do anything without the residents permission. Do you want people meddling in your business without your permission?”

-Kathie Gately, SLTCO
The right to make independent choices is a key right for residents of nursing homes. These include the right to make personal decisions like managing one’s own finances. To the average citizen, this is an inherent right of being a free American. In long-term care facilities, however, residents being financially exploited is an ongoing issue that long-term care ombudsmen deal with. According to AARP about 60 percent of Adult Protective Services cases of financial abuse nationwide involved an adult child of the resident.

Financial or material exploitation is defined as the illegal or improper use of funds, property or assets of a nursing home resident. It can include cashing a resident’s check without permission, forging a signature, stealing money or property, deceiving the resident into signing any document and improper use of power of attorney.

Other instances include, unexplained bank withdrawals, checks written with “loan” or “gift” on them, sudden appearance of previously uninvolved relatives claiming a right to an elder’s affairs or possessions.

“The most common sort of financial exploitation I’ve seen is when resident’s family members receive the monies and simply do not deliver the money to the resident.” Kathie Gately, State LTC Ombudsman, stated. “If we suspect financial exploitation, we must act by being a voice for the resident.” As she went on to address the concerns that both the Office of Long-Term Care, and the State Ombudsman’s office share.

But what can you do to stop the financial exploitation of a nursing home resident?

“You want to make sure the resident is aware of what is happening and allow them to take action,” stated Robyn Moss, Regional Ombudsman.

After the resident, facility and financial institution are made aware of the financial exploitation, and proof is available, justice will be brought, if not from the resident, or facility, then the Arkansas Attorney General’s office.

CVO Spotlight:

Marilyn Jarrett, Region I
Certified Volunteer Long-Term Care Ombudsman since 2004

1. What brought you to the Arkansas Volunteer Ombudsman program? Approximately 11 years ago there were no Ombudsman volunteers in Arkansas. I told them I would try for a few months. That was over 10 years ago and I saw a need to stay with the program. It was an honor knowing I was the second in the state.

2. What do you enjoy about it? Getting to know the meaning of growing old gracefully and how it could be if you choose to be difficult.

3. Why should someone be a volunteer Ombudsman? The residents seem to receive help faster when they know we are watching and if they are not being attentive enough I will ask them to see about the resident that may not be able to reach call lamp. Care for the elderly puts us in perspective of where we may be someday.

4. What is the hardest part of being a Volunteer Ombudsman? Getting acquainted and then seeing them not getting attention needed with no family. The ones with family coming everyday are better by far. I try to be a friendly help for all and keep smile for those hurting. It seems so (bad) sad that it cost so much to reside there and not get the care they should. We need to keep on keeping on. Family should not need to bring items, food or otherwise that is included in care they are to get.

We thank you, Marilyn, for all your years of service and care for our beloved residents.
At their best, culture change efforts epitomize “celebrating age,” but providers must work to maintain a sense of ownership among residents and their families. As more organizations embrace the tenets of person-centered care, they are creating homey environments; bringing out the best in older adults with activities, meals and other functions; and working to make the phrase “person-centered” more than mere rhetoric. Even so, it’s easy to see how “culture change” programs could default to being top-down efforts.

How can providers create a sense of ownership among residents and their families? How can they be sure that residents are a driving force in creating change? Do they feel the organization listens to them, respects their ideas and works to adapt to what they want?

“At the heart of culture change is the desire to make sure that the care is person-centered and person-directed, so the voice of the elders is a critical element,” says Peter Reed, CEO of the Pioneer Network. “It is really important that you are asking about resident preferences and needs.”

“The essence of changing the culture is for people to be engaged and involved,” says LaVrene Norton, executive leader of Action Pact in Milwaukee. “It’s a vital principle that you have to think through and plan for. Otherwise, you are doing to residents instead of assuring they are directing their own lives.”

Norton adds that high-performing organizations continually strive to do better. Early research shows benefits to providing a healthy living environment for people too frail to live alone. “Living in a household makes life a lot better for a person,” she says. “They are more in charge of their lives, and they are happier.”

“When you look at culture change and the idea of top-down vs. bottom-up,” says Reed, “decision making really is about a deep transformation, a deep shift in how people think about these homes. There is a desire to make them a place people would want to live.”

James Farnan, administrator of Eddy Village Green, a 16-building Green House® community in Cohoes, N.Y., says the transition to the model occurred when leadership recognized it needed to do things better and allow residents to live the lives they want to live and not confine them to institutions.

“The houses are about opportunity,” Farnan adds. “People have more options than they had in the old model.”

It’s like their prom:

Nursing home residents gather for lunch and discussion of care issues

Bowling Green, KY - About 50 area nursing home residents gathered at Warren Central High School to discuss issues facing long-term care facilities. They were there as part of an annual conference sponsored by the Barren River Long Term Care Ombudsman Program. “We’re advocates for the resident and work to resolve any kind of issue they have,” District Ombudsman Teresa Whitaker said. Ombudsmen visit nursing homes in their 10-county district to educate residents about their rights and help resolve any problems going on in their facility.

“A lot of people think when they move into a care facility, they lose their rights,” Whitaker said. “We show them that’s not the case. They’re paying for a service.” Ombudsmen visits are also partly to socialize with residents, because 60 percent of them get, at most, one visitor a year, Whitaker said.

Each year at the conference, residents break into sessions where they discuss nursing home issues, she said. They also get lunch served at tables decorated by local organizations. “The residents love it because it makes them feel like they’re part of the community again,” Whitaker said. Martha Morgan, table decorator chairwoman for the Ombudsman Advisory Council, said residents feel special during the lunch. “So many times, they only eat in the nursing home, so they see this as a banquet,” Morgan said. “It’s like their prom.” Dana Bradley, director of Western Kentucky University’s Center for Gerontology, volunteers at the conference along with her students each year.

“It reminds us of all the possibilities that we have as we age,” Bradley said. “Any one of us could be one of these residents.” People shouldn’t forget that nursing home residents are members of the community just be-
cause we don’t see them every day, Bradley said. Molly Copas, a resident of Colonial Manor Care and Rehabilitation Center in Bowling Green, said she enjoyed the conference and liked learning how others felt about their nursing homes. “I’m pleased with the place I’m in, but I just miss being at home and doing my own stuff,” Copas said. She said the staff at Colonial Manor understands that residents would rather be at home, and coming to this conference helps her see that residents of other nursing homes could be in worse situations. “It helps us go away feeling that we’re blessed,” Copas said. Sandy Bailey, who also lives in Colonial Manor, came to the conference for the second year in a row. “It’s a nice way to meet new people and I enjoyed this table,” she said.

Article By Laurel Wilson

If I'm Doing the Right Thing, Why Do I Feel So Guilty?

You’ve just completed the process of admitting a family member to a long-term care facility and you’re faced with the guilty feeling that you may have let that person down. Even though you may have spent a long time trying to cope with caring for the loved one yourself and know that this is the only way to go, the negative thoughts persist.

Be assured that these emotions are not unique and you are not alone. Nearly every family in your position experiences some degree of trauma which may include guilt, anxiety or even anger at having to take responsibility for making the placement decision. These are understandable reactions. And there are positive ways to deal with them.

• Talking over your problems with other families who have been in the same situation can be helpful. They understand your difficulties and may have good advice to offer.
• Most facilities recognize the importance of aiding family members in making the critical transition. “Each time you admit a resident to your facility, you are, in a manner of speaking, admitting that resident's family as well,” says Suzanne Geffen Mintz of the National Family Caregivers Association. Family members are urged to seek the counsel of the facility's social service worker for your concerns and answer your questions.
• Avail yourself of any supports that the facility has in place to aid families, such as: Family councils, Resident Councils, a caregivers resource center which offers books, pamphlets, newsletters and videos on a variety of subjects.
• Perhaps there is (or you might organize) a family council run by family members as a way of addressing grievances, organizing activities and communicating with the administration.
• Respond to invitations to contribute to your loved one's care by helping at mealtime or accompanying the resident to an activity. It has been established that such caring participation in the person's life makes family members feel more needed and lessens the sense of frustration or guilt.
• When appropriate, the transition may be made easier for the new resident and the family by a clergy member, who could include religious reading, hymns and poems.
• It is very important to keep the lines of communication open with the staff of the facility. Don't be afraid to ask questions about the facility's routine and practices. This will ensure your peace of mind about the loved one's care. The facility's administrators want you to feel secure. Bottled-up anxiety can cause misunderstanding and result in fewer of the family visits that are so vital to the resident.
• Family members who live far away from the facility should be encouraged to make phone calls and send letters to the resident. Sending audio and video cassettes is an especially good way to keep the loved one in touch.
• Take advantage of suggestions the facility may have available to make visits more succ-
CREATE: Coordinated Response to Elder Abuse Training Effort

The CREATE program is funded through a grant awarded to the Department of Human Services by the Office of Violence Against Women and the Department of Justice. The program is designed to provide training programs to assist law enforcement, prosecutors, governmental agencies, victim assistants, and officers of federal, state and local courts in recognizing, addressing, investigating and prosecuting cases of elder abuse, neglect and exploitation to include sexual assault, domestic violence, or stalking victims who are 50 or older or are 18 and incapacitated or impaired.

The need for this program was generated due to:
- No specific group or program that focuses solely on older adult victims of violence or exploitation
- Lack of coordination between agencies
- No safe haven from abusers
- Understaffed service providers

Currently, Washington County in Northwest Arkansas will be the first to undertake the training.

For any questions about the CREATE program, please contact Ms. Gwen Erwin-McLarty, Program Administrator, Division of Aging and Adult Services, at 501-320-6557.
Thank you so much for all you do!
We can’t wait: Administration announces new steps to fight Alzheimer’s disease

The Obama Administration today announced new efforts to fight Alzheimer’s disease, including immediately making an additional $50 million available for cutting-edge Alzheimer’s research. In addition, the administration announced that its Fiscal Year 2013 budget will boost funding for Alzheimer’s research by $80 million. Today’s announcement also includes an additional $26 million in caregiver support, provider education, public awareness and improvements in data infrastructure.

In January 2011, President Obama signed the National Alzheimer’s Project Act, which calls for an aggressive and coordinated national Alzheimer’s disease plan. The Act also establishes an Advisory Council on Alzheimer’s Research, Care, and Services, which brings together some of the Nation’s foremost experts on Alzheimer’s disease to inform the development of the national plan. The preliminary framework for the National Alzheimer’s Disease Plan identifies key goals including preventing and treating Alzheimer’s disease by 2025. As work on the plan continues, the Obama Administration is taking action.

“Today’s announcement reflects this administration’s commitment to confronting Alzheimer’s, a disease that takes a devastating toll on millions of Americans,” said HHS Secretary Kathleen Sebelius. “We can’t wait to act; reducing the burden of Alzheimer’s disease on patients and their families is an urgent national priority.”

As many as 5.1 million Americans currently suffer from Alzheimer’s disease, which is a progressive, irreversible brain disorder that destroys memory and thinking skills. With the aging of the U.S. population, the number of people with Alzheimer’s disease could more than double by 2050.

“These projections are simply staggering,” said National Institutes of Health (NIH) Director Francis S. Collins, M.D., Ph.D. “This new funding will accelerate NIH’s effort to use the power of science to develop new ways of helping people with Alzheimer’s disease and those at risk.”

Together, the fiscal years 2012 and 2013 investments total $130 million in new Alzheimer’s research funding over two years – over 25 percent more than the current annual Alzheimer’s research investment.

The additional NIH research funding will support both basic and clinical research. Investments will include research to identify genes that increase the risk of Alzheimer’s disease and testing therapies in individuals at the highest risk for the disease. On the clinical side, the funds may be used to expand efforts to move new therapeutic approaches into clinical trials and to develop better databases to assess the nation’s burden of cognitive impairment and dementia.

The initiative announced today also includes $26 million to support additional goals in the preliminary National Alzheimer’s Disease Plan. While the plan continues to be developed, experts have identified several goals that will be supported by today’s announcement, including support for caregivers in the community, improving health care provider training, and raising public awareness.

“These new funds will help increase our understanding about how to manage Alzheimer’s disease, especially those services that allow families to plan in the early stages and support family caregivers,” said HHS Assistant Secretary for Aging Kathy Greenlee.

Can you believe that we are already one-third of the way into 2012? Time as an LTC Ombudsman seems to fly doesn’t it! As you all know, each year we develop an LTC Ombudsman campaign goal and at our LTC Ombudsman 2011 retreat we discussed this year’s campaign of developing and reviving Family Councils. “Family Councils – Building Foundations” will be at the forefront of our Ombudsman work. We know that one of the standards set in the Older Americans Act for the statewide Ombudsman program is to help develop Family Council and be an intricate part of their positive working relationship with facilities and sustainability. I am excited to be a part of this Arkansas LTC Ombudsman campaign and truly feel that those we serve will greatly benefit from our work.

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