

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

Engaging Families & LTC Ombudsmen to Improve Dementia Care: Project Results & Recommendations

Dementia care is a growing concern, as our population ages and more people live longer with Alzheimer’s and other forms of dementia, particularly in nursing homes. The inappropriate use of antipsychotic drugs on people with dementia compounds these concerns for many individuals and families. Close to 20% of nursing home residents are currently (2017) being given powerful and dangerous antipsychotics, though less than two percent (2%) of the population will ever have a diagnosis of a mental illness that CMS recognizes as potentially appropriate in its risk-adjustment for antipsychotic drug use. This is especially alarming because these drugs are *not* clinically indicated for treatment of symptoms related to dementia and *are* associated with increased risk of death in the elderly. A 2011 study on antipsychotic drug use by the Office of the Inspector General of the U.S. Department of Health and Human Services found that too many nursing homes “fail to comply with federal regulations designed to prevent overmedication.” The US Inspector General stated that “Government, taxpayers, nursing home residents, as well as their families and caregivers should be outraged - and seek solutions.”

In response to these findings and the Inspector General’s call to action, LTCCC and other advocates have been working to reduce the inappropriate use of antipsychotics and improve dementia care, particularly in our nursing homes. The purpose of the project discussed in this report was to engage and educate Family Councils and LTC Ombudsmen on some of the issues we identified as most relevant to good dementia care and the reduction of inappropriate and dangerous antipsychotic drugging. LTCCC’s executive director attended meetings of two nursing home Family Councils and the Alliance of NY Family Councils. During each meeting he discussed a relevant dementia care standard and how that standard supported their advocacy for better care and the avoidance of inappropriate drugging. A short fact sheet on each issue was distributed at each meeting to support the attendees in their future advocacy. These fact sheets were compiled into the **Dementia Care Advocacy Toolkit**. The Toolkit, available in the Learning Center of LTCCC’s website, www.nursinghome411.org, provides residents, families and those who work with them easy-to-use and accessible information to support improved care, quality of life and dignity for people with dementia now and in the future.

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Project Results

As noted above, this project focused on engaging and educating nursing home families and LTC ombudsmen on dementia care standards, appropriate care practices and concerns about the widespread use of antipsychotic drugs on nursing home residents. The goal was to provide them with the knowledge and skills necessary to advocate effectively on these issues in their nursing homes. Our underlying purpose, in developing the project, was to address what we identified as an unmet need: while the national campaign to reduce inappropriate antipsychotic drugging of nursing home residents with dementia has focused on educating and engaging providers, it has largely ignored residents' families and the LTC ombudsmen, who work closely with families and residents, to improve nursing home care and quality of life. In the absence of enforcement of the basic standards prohibiting inappropriate drugging and the use of chemical restraints, we felt that it was critical to empower families and ombudsmen so that they can advocate effectively for residents with dementia.¹

There were two principal results expected from this project: (1) Participants would have increased knowledge of, and ability to advocate on, dementia care and antipsychotic drugging standards and (2) Based on the programs and feedback received from participants, we would develop a useful "toolkit" to support resident-centered advocacy to improve dementia care and reduce inappropriate antipsychotic drugging that could be used by families, LTC ombudsmen and other advocates in the future.

Timeline

1987: U.S. Nursing Home Reform Law prohibits inappropriate drugging and the use of chemical restraints.

2004: FDA issues "black-box" warning against use of antipsychotics on elderly with dementia.

2011: Inspector General decries failure of "too many" nursing homes to comply with minimum standards for unnecessary drug use.

2011: U.S. Senate hearing: "Overprescribed: The Human and Taxpayers' Cost of Antipsychotics in Nursing Homes."

2012: CMS launches national campaign to stop widespread inappropriate drugging.

2015: Close to one in five nursing home residents still being medicated with dangerous antipsychotics.

¹ For more on the antipsychotic drugging issue and the national campaign see our website, www.nursinghome411.org.

1. Participant Knowledge of Dementia Care Standards

We conducted trainings over an 18 month period (17 monthly programs at meetings of two nursing home family councils and 14 programs for the Alliance of NY Family Councils²).

Participants learned about:

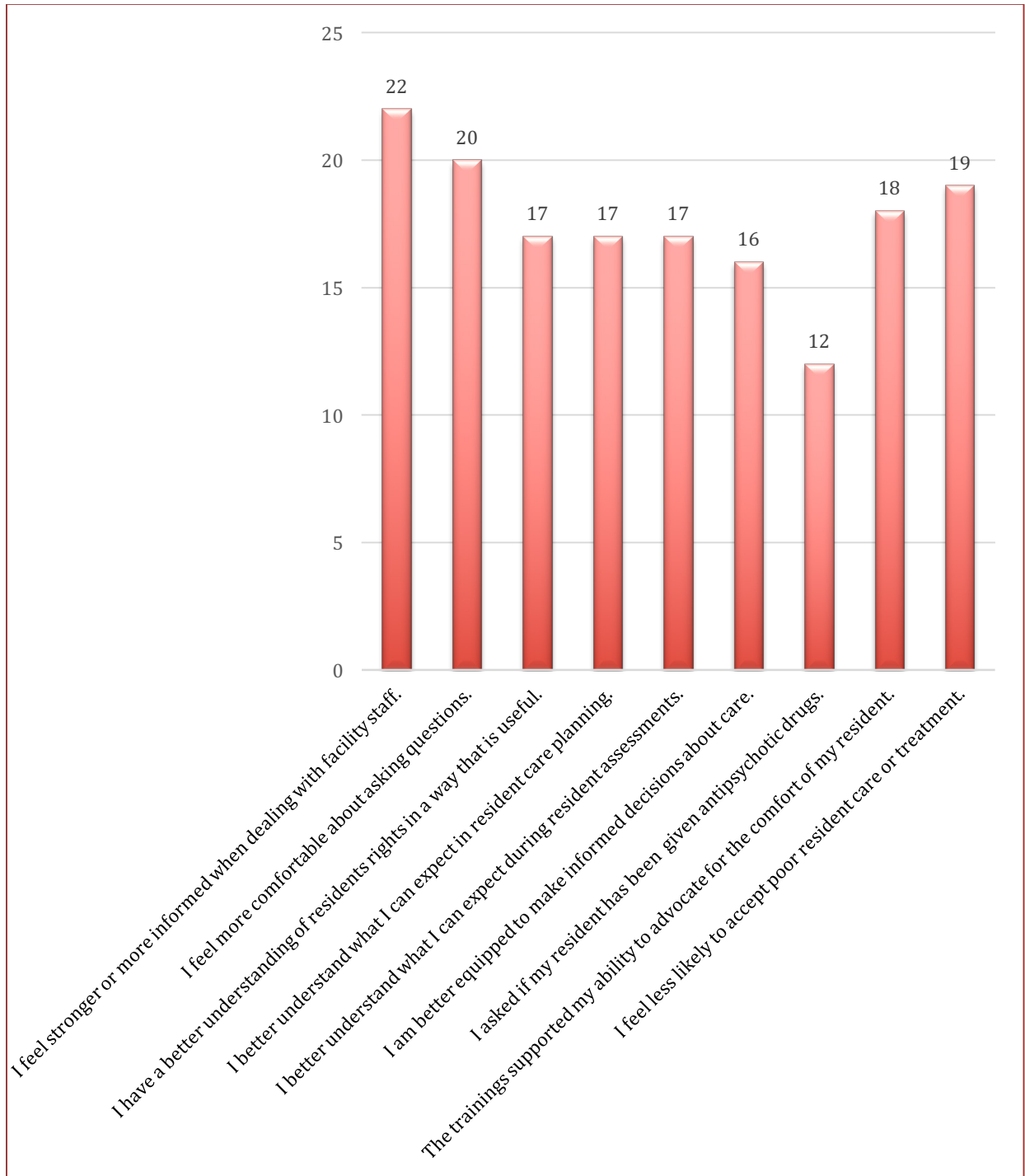
1. Basics of Nursing Home Care: Nursing home laws and standards that form the basis for good dementia care;
2. The Antipsychotic Drugging Problem: The widespread use of antipsychotic (AP) drugs as a form of chemical restraint, what AP drugs are, protocols for their use (including gradual dose reduction and non-pharmacological approaches), federal guidelines that are relevant to their residents and their advocacy for better care, etc...;
3. Relevant Care Standards: Principal federal regulation relevant to good dementia care and how these regulations can be used to support their advocacy; and
4. Advocacy: Participants learned what questions they should ask and of whom they should ask them when they have concerns about the medications their resident is receiving. They learned about the different entities responsible for quality of care and oversight – both within and outside of the nursing home – and how to support their advocacy at each level through knowledge of their (resident) rights, record-keeping, etc....

At the end of the 18 months we conducted an anonymous survey of participants. We received a total of 31 respondents to the survey: 25 family members, two residents, two LTC ombudsmen and one person identified as both resident & family member. All of the respondents (100%) indicated that the programs were helpful to them. The survey asked that if a respondent responded “yes” to the question of whether they found the programs helpful to tell us how by choosing among the following options. [See following page for chart of responses.]

- I feel stronger or more informed when dealing with facility staff.
- I feel more comfortable about asking questions.
- I have a better understanding of residents’ rights in a way that is useful.
- I better understand what I can expect in resident care planning.
- I better understand what I can expect during resident assessments.
- I am better equipped to make informed decisions about care.
- I asked if my resident has been given antipsychotic drugs.
- The trainings supported my ability to advocate for the comfort of my resident.
- I feel less likely to accept poor resident care or treatment.
- Other (please specify).

² The Alliance of New York Family Councils is an organization of family members and friends of nursing home residents in New York. Its website is <http://anyfc.org/>.

Family/Ombudsman/Resident Survey Results



Comments From Survey Participants

- “I feel more empowered, more knowledgeable about being an effective care giver and looking after the commonwealth.”
- “This meeting very informative about how this nursing home is working.”
- “Communication is very important on both sides for your love-one to get the Best care.”
- “I need more about the program.”
- “The trainings were outstanding and have left me wanting more of them - ongoingly!”
- “They advocate for the resident. Nursing Homes aren't concerned about resident care improvements.”
- “I am just grateful for the comprehensive information provided. Empowerment.”

2. Dementia Care Advocacy Toolkit

Each of the training programs was accompanied by a handout discussing the regulatory standard that was the topic of the program and providing, where possible and appropriate, a checklist for resident-centered advocacy. Following the 18 months of trainings, these materials were revised (based on feedback from families and ombudsmen, as well as the recent revision of federal nursing home requirements) and compiled into a toolkit to support current and future advocacy to improve dementia care and reduce inappropriate antipsychotic drugging. The toolkit is available for free on our website, www.nursinghome411.org, on a dedicated page.³ It includes individual factsheets on a range of relevant issues and problems, including:

- Dementia Care Considerations
- Dementia Care Practices
- Dementia Care & Psychotropic Drugs
- Non-Pharmacological Approaches to Dementia Care
- Resident Dignity & Quality of Life
- Standards for a Safe Environment
- Resident Assessment & Care Planning
- Care Planning Requirements
- Informed Consent
- Resident & Family Record-keeping
- Standards for People Providing Care

³ <http://nursinghome411.org/learning-center/dementia-care-advocacy-toolkit/>.

- Standards for Nursing Home Services
- Standard of Care to Ensure Resident Wellbeing

The launch of the toolkit coincided with a free, two-part webinar on dementia care. The program recordings and presentations are also available on our website as well as our YouTube channel.⁴

Recommendations

Though the scope of this project was small (in respect to the numbers of family members and ombudsmen who participated), the length of the project activities and extent to which we were able to provide ongoing engagement and education to the family councils and LTC ombudsman provide, we believe, a meaningful basis for making recommendations about the value of such efforts. The informal feedback we received (and continue to receive) from family members and ombudsmen, as well as the results of the anonymous survey of participants (discussed above), indicate that family members and ombudsmen desire information on residents rights and care standards and utilize this information to the benefit of residents in their facilities. Thus, we recommend:

1. **Improved Government Outreach & Education.** CMS and the state Survey Agencies should increase outreach to and engagement of nursing home residents, families and advocates (in particular LTC ombudsmen) on resident rights and standards related to care, quality of life and dignity on an ongoing basis. The National Partnership to Improve Dementia Care has focused largely on provider education and engagement. Nursing homes have been required under federal law and regulations to provide appropriate dementia care and avoid inappropriate drugging for over 25 years. In short, they are already being paid to know and meet these standards. We believe that resources would be better allocated to fostering the knowledge and skills of those stakeholders who are not already being paid to meet these standards, namely the residents, their families and those who work with them.
2. **Strengthen Resident & Family Councils.** It has long been recognized that the presence of an active resident or family council improves care and quality of life in a nursing home. Yet, too often, these groups face significant challenges to sustaining their activities, in particular effective advocacy.
 - a. Philanthropic Support. We urge the philanthropy community to dedicate resources to facilitating the development and sustaining of family and resident councils. In particular, we encourage foundations and others interested in funding improvement in nursing home care to consider the important role that resident-centered advocacy can have in achieving these goals.
 - b. Grassroots Support. For a myriad of reasons, being an active member of a resident or family council can be challenging. Maintaining an active council is also challenging. We strongly encourage residents and families to support one

⁴ <https://www.youtube.com/channel/UCSfczzeXNn5DS8EtECRskIQ>.

another in developing and sustaining a council in their nursing homes and to avail themselves (to the extent possible) of resources available online to support and inform their work. Likewise, we urge LTC ombudsmen and advocates to encourage and support the residents and families with whom they work.

3. **Strengthen LTC Ombudsman Programs.** Ombudsmen are essential to promoting good care and minimizing (or preventing) incidents of substandard care, abuse and neglect. However, low financial support over the years and (the resulting) over-reliance on volunteers puts unnecessary strain on ombudsmen and their programs. In our project we found that ombudsman staff and volunteers generally had a keen interest in nursing home standards and in sharing what they learned with others (including residents, family members and direct care staff) in their nursing homes. We believe that even a relatively small increase in government (or philanthropic) financial support would have significant and far-reaching benefits in respect to improved resident-centered knowledge and capacity for advocacy.

Acknowledgements

We would like to thank the Family Councils of Terence Cardinal Cooke and The Riverside nursing homes, and the Family Council representatives in the Alliance of NY Family Councils (www.anyfc.org), for agreeing to work with us in this project and for allowing us to participate in their meetings and efforts. We learned much from many of the family members (who shall remain anonymous), but would like to especially thank Charles Gourgey and Gilbert Sabater for their help in supporting the project and its goals in Councils across New York.

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For more information and resource on dementia care and other nursing home standards, including the free Dementia Care Advocacy Toolkit, visit www.nursinghome411.org.