Engaging & Educating Nursing Home Families & Ombudsmen to Improve Dementia Care

Richard Mollot, Long Term Care Community Coalition

www.nursinghome411.org
What is the Long Term Care Community Coalition?

- **LTCCC:** A nonprofit organization dedicated to improving care and quality of life for the elderly and adult disabled who are in long term care (LTC).

- **Our focus:** Principally, residents in nursing homes and assisted living.

- **What we do:** Systemic Research, Analysis & Advocacy.
  - Research and analysis on federal and state laws and regulations affecting nursing home and assisted living care;
  - Education and engagement of state and federal policymakers & regulators;
  - Education and training of consumers, families, LTC Ombudsmen, providers and other stakeholders.

- **Coalition members in NY include:** LTC Ombudsman Programs, AARP NY, the Alliance of NY Family Councils, several Alzheimer’s Association Chapters, other senior and disabled organizations.

Today’s Program

- Description of LTCCC’s project: *Engaging & Educating Nursing Home Families & Ombudsmen to Improve Dementia Care.*
- Review of some of the relevant standards that families and ombudsmen should be aware of, and the tools we have developed that **YOU** can use to support resident-centered advocacy.
- Time for discussion, questions and answers.
About the Project

- Poor dementia care is a persistent, widespread problem.
- Too many nursing homes continue to use powerful and dangerous antipsychotic drugs:
  - Close to 20% of US nursing home residents are given antipsychotics, though less than 2% will ever have a diagnosis which CMS considers appropriate for these drugs.
  - Antipsychotics have an FDA “black-box warning” against use on elderly people with dementia due to high risk of Parkinsonism, falls, strokes, heart attack and death.
  - Antipsychotics are not indicated for so-called dementia related psychosis.
  - Antipsychotics are not effective for more than a very short period of time on so-called “Behavioral & Psychological Symptoms of Dementia.”
  - Despite federal law, too many nursing homes use antipsychotics as a chemical restraint, to sedate residents (in place of providing the care and services residents need).
- Too many nursing homes treat dementia “behaviors” as a disease, rather than as communication.
- In speaking with LTC Ombudsmen, Residents & Families, we frequently find that they know when something is wrong, but often don’t know about the laws and standards that can support them in getting their problem fixed.

*At the end of the presentation we will provide links to resources on dementia care & antipsychotic drugging rates for all US nursing homes.*
About the Project

- In 2013, we held a successful full-day conference on dementia care and reducing antipsychotic drugging, bringing together nursing home staff, family members, ombudsmen and others who work with residents.

- To follow-up on this work, LTCCC received funding from the Samuels Foundation to conduct focused trainings for two years with two nursing home family councils and with the Alliance of NY Family Councils (www.anyfc.org).

- Every month, we present a short training at the family council meeting on a relevant nursing home standard, providing a hand out that residents, families and ombudsmen can use in the future to support their advocacy.

- Because other family councils were interested in the trainings, we began conducting webinars every other month, open to all residents, family councils and ombudsmen in NYC.

- The project will culminate in a free toolkit for resident-centered advocacy to improve dementia care and reduce antipsychotic drugging.

The free toolkit will be available on our website, www.nursinghome411.org, in Spring 2017.
Nursing Home Standards: Residents’ Rights

- **Dignity:** Every resident, including those with dementia, has the right to be treated with dignity and respect and to live in a comfortable environment.

- **Necessary Care & Services:** Every resident, no matter who pays for her care, has the right to receive the care and services necessary to attain and maintain highest possible well-being and functioning.

- **Informed Decision-Making:** Residents have the right to be informed about the risks and benefits of any medication or treatment in language he or she can understand.

- **Right to Refuse:** Residents have the right to refuse a medication or treatment.

- **Freedom from Chemical Restraints:** It is against the law to give medications that do not benefit the resident, such as for convenience of staff.
Selected Nursing Home Standards: Antipsychotic Drugging

LONG TERM CARE COMMUNITY COALITION
Advancing Quality, Dignity & Justice

CONSUMER FACTSHEET #6: ANTIPSYCHOTIC DRUGGING
This factsheet discusses two of the principal antipsychotic drugging standards and how you can use them to advocate for your resident. Following are the standards with descriptions excerpted from the federal regulations. [The brackets provide the number for the relevant federal regulation (CFR).]

STANDARD 1: PHARMACY SERVICES 1 [42 CFR §483.45]
- Residents who have not used psychotropic drugs are not given these drugs unless the medication is necessary to treat a specific condition as diagnosed and documented in the clinical record;
- Residents who use psychotropic drugs receive gradual dose reductions, and behavioral interventions, unless clinically contraindicated, in an effort to discontinue these drugs;
- Residents do not receive psychotropic drugs pursuant to a PRN (dispense as needed) order unless that medication is necessary to treat a diagnosed specific condition that is documented in the clinical record; and
- PRN orders for psychotropic drugs are limited to 14 days.

STANDARD 2: BEHAVIORAL HEALTH SERVICES 2 [42 CFR §483.40]
- Each resident must receive and the facility must provide the necessary behavioral health care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care. Behavioral health encompasses a resident’s whole emotional and mental well-being.
- The facility must have sufficient staff who provide direct services to residents with the appropriate competencies and skills sets to provide nursing and related services to assure resident safety and attain or maintain the highest practicable physical, mental and psychosocial wellbeing of each resident, as determined by resident assessments and individual plans of care.
- These competencies and skills sets include, but are not limited to, knowledge of and appropriate training and supervision for:
  1. Caring for residents with mental and psychosocial disorders... and
  2. Implementing non-pharmacological interventions.
- Based on the comprehensive assessment of a resident, the facility must ensure that..., A resident who displays or is diagnosed with dementia, receives the appropriate treatment and services to attain or maintain his or her highest practicable physical, mental, and psychosocial well-being.

QUESTIONS TO ASK WHEN ANTIPSYCHOTIC DRUGS ARE GIVEN OR PROPOSED
1. What specific, documented symptoms or behaviors prompted use of the drug(s)?
2. Have all possible medical, emotional and environmental causes been ruled out (such as fear, boredom, constipation, an underlying infection or change in caregiving routine)?
3. What alternative treatments have been tried? What other alternatives are there?
4. What are the potential benefits and risks of the drug?
5. Is this the lowest possible dosage of the drug?
6. How will the drug effect the resident medically and mentally?
7. What is the planned time frame for treatment with the drug?
8. What is the plan for employing non-pharmacological approaches?
9. What is the plan for gradual dose-reduction?
10. When and how often will the need for the drug be reassessed?
11. How will side effects be monitored?

THINGS TO DO
- Review medications. Periodically request a complete list of current medications from the nursing home and/or review the resident’s medication administration records kept by the facility (especially if unauthorized drugging is suspected).
- Care plan meeting. Ask for a care plan meeting to discuss the need for proposed antipsychotic drugs. Use the care plan meeting to determine if the drug is really needed and whether the home has carefully considered all alternatives. See box, above, for Questions to Ask.
- Know about federal standards & guidelines. They are an important resource for knowing the standards of care and legal expectations for the treatment of residents. Remember: Its hard to advocate for your resident’s rights if you don’t know what they are!
- File a complaint. If you discover that psychotropic drugs are being used without consent, and you are not able to make headway with facility staff, you can notify your local LTC Ombudsman [www.ltcombudsman.org] and/or file a complaint with your state survey agency [https://www.medicare.gov/nursinghomecompare/resources/state-websites.html] and/or your state Medicaid Fraud Control Unit [http://www.namfu.net/medicaid-fraud-control-unit1.php].

RESOURCES
- WWW.NURSINGHOME411.ORG, LTCCC’s website includes materials on the relevant standards for nursing home care, a listing of antipsychotic drug names, drugging rates and other data for all US nursing homes and more.
- WWW.THECONSUMERVOICE.ORG, The Consumer Voice has numerous materials and resources for residents, family members and LTC Ombudsmen.
- WWW.MEDICARE.GOV/NURSINGHOMECOMPARE, The federal website provides information on individual nursing homes nationwide.

1 Formerly Free From Unnecessary Drugs [F-329 - 42 CFR 483.25(i)(2)(i, iii)]. The regulation provides exceptions to the PRN 14 day limitation based on evaluation by physician or prescribing practitioner.
2 Formerly Necessary Care for Highest Practicable Well-being [F-309 - 42 CFR 483.25].
Selected Nursing Home Standards: Resident Assessment & Care Planning

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CONSUMER FACTSHEET #9: RESIDENT ASSESSMENT & CARE PLANNING

There are many standards which nursing homes are required to follow in order to ensure that residents receive appropriate care, have a good quality of life and are treated with dignity. In the absence of effective government enforcement, YOU can use these standards as a basis for advocating in your nursing home. Following are two important STANDARDS FOR RESIDENT ASSESSMENT & CARE PLANNING with information that can help you understand and use them to advocate for your resident. [Note: The brackets provide the relevant federal regulation (CFR). This information is included as a reference for you in the future.]

STANDARD 1: RESIDENT ASSESSMENT
[42 CFR 483.20]
- The facility must conduct initially and periodically a comprehensive, accurate, standardized reproducible assessment of each resident’s functional capacity.
- A facility must make a comprehensive assessment of a resident’s needs, strengths, goals, life history and preferences, using the resident assessment instrument (RAI) specified by CMS.
  The assessment must include at least the following:
  o Identification and demographic information.
  o Customary routine.
  o Cognitive patterns.
  o Communication.
  o Vision.
  o Mood and behavior patterns.
  o Psychosocial well-being.
  o Physical functioning and structural problems.
  o Continence.
  o Disease diagnoses and health conditions.
  o Dental and nutritional status.
  o Skin condition.
  o Activity pursuit.
  o Medications.
  o Special treatments and procedures.
  o Discharge potential.
  o Documentation of summary information regarding the additional assessment performed through the resident assessment protocols.
- Documentation of participation in assessment. The assessment process must include direct observation and communication with the resident, as well as communication with licensed and nonlicensed direct care staff members on all shifts.

STANDARD 2: COMPREHENSIVE CARE PLANS
[42 CFR 483.20(k)]
- The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet a resident’s medical, nursing, and mental and psychosocial needs that are identified in the comprehensive assessment.
- The care plan must describe the following:
  o The services that are to be furnished to attain or maintain the resident’s highest practicable physical, mental, and psychosocial well-being...; and
  o Any services that would otherwise be required... but are not provided due to the resident’s exercise of rights... [such as] the right to refuse treatment....
- A comprehensive care plan must be—
  o Developed within 7 days after completion of the comprehensive assessment;
  o Prepared by an interdisciplinary team, that includes the attending physician, a registered nurse with responsibility for the resident, and other appropriate staff in disciplines as determined by the resident’s needs, and, to the extent practicable, the participation of the resident, the resident’s family or the resident’s legal representative; and
  o Periodically reviewed and revised by a team of qualified persons after each assessment.
- The services provided or arranged by the facility must—
  o Meet professional standards of quality; and
  o Be provided by qualified persons in accordance with each resident’s written plan of care.

Relevant Points From the Federal Guidelines
- A facility must make an assessment of the resident’s capacity, needs and preferences.
- The assessment must include a wide range of resident needs and abilities, including customary routine, cognitive patterns, mood, ability to and methods of communication, physical, dental and nutritional status.
- A facility is expected to primarily rely on direct observation and communication with the resident in order to assess his or her functional capacity.
- In addition to direct observation and communication with the resident, the facility must use a variety of other sources, including communication with care staff on all shifts.
- A resident’s care plan “must describe... the services to be furnished to attain or maintain the resident’s highest practicable physical, mental and psychosocial well-being...”
- The care plan must be based on the assessment. In other words, it must come from the resident’s needs and abilities, not the services which the nursing home decides to provide based on its financial (or other) priorities.

RESOURCES
- WWW.NURSINGHOME411.ORG. LTCCC’s website includes materials on the relevant standards for nursing home care and numerous resources for consumers, LTC ombudsmen & caregivers.
- WWW.THECONSUMERVOICE.ORG. The Consumer Voice’s website has a variety of materials and resources for residents, family members and LTC Ombudsmen.

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Use this checklist to identify what is important to YOU when you have a resident assessment!

1 The 2016 federal regulation keeps the previous CFR number. The previous F-tag for this standard was F-272.
WHY are Assessment & Care Planning Important?

BECAUSE this is when your resident’s needs are determined and where the facility sets forth how it is going to meet those needs.
Selected Nursing Home Standards: Expected Practices for Dementia Care

LONG TERM CARE COALITION
Advancing Quality, Dignity & Justice

Basic Standards of Practice for Good Dementia Care & Avoiding Inappropriate Antipsychotic Drugging

Earlier handouts in this toolkit discussed the important regulations that lay out what nursing homes are required to do to protect residents, including those with dementia, from inappropriate antipsychotic drugging and provide each of them with good and appropriate services to meet their needs as individuals. This handout focuses on the “Behavioral & Psychological Symptoms of Dementia” (BPSD): what they are and what the nursing home should be doing to address them.

Examples of Behaviors That a Resident Might Exhibit Which Results in Antipsychotic Drugging

- Aggressive behavior towards care staff, other residents or loved ones
- Abnormal/repetitive vocalizations
- Sleep disturbances
- Wandering

What are some important things to know about “Behavioral & Psychological Symptoms of Dementia” (BPSD)?

- The only BPSD that may be responsive to or appropriate for antipsychotic treatment are aggression, agitation, or psychotic symptoms that pose an immediate risk for harm.
- Antipsychotic medications are only moderately effective for most BPSD and should be trialed as the last resort for a limited period of time when there is an immediate risk of harm.
- Not all psychotic symptoms necessarily require pharmacologic treatment of any kind (i.e., hallucinations that do not distress the person with dementia).
- It is important to consider other social, psychological and physical needs that a person might have that may result in BPSD, especially pain, which is highly prevalent among older persons.
- Most BPSD are responsive to non-pharmacological approaches. The approach should be based on an assessment of possible causes and individualized to the person’s abilities and physical/emotional/social needs.

Non-Pharmacologic Approaches

Nursing homes are required to make changes to the care, treatment and environment of a resident to appropriately address and alleviate BPSD. Following are some examples of approaches that might be taken, depending on the specific needs of the resident:

- Clinical. Identifying if a resident is in pain or uncomfortable and taking steps to address and provide relief.
- Environmental. Identifying environmental causes and taking steps to address them, such as reducing noise or visual stimulation, providing an area for safe wandering or creating a home-like atmosphere to reduce a resident’s stress.
- Staff Training. Educating care staff on:
  - Communication skills;
  - Person-centered bathing;
  - Minimizing and avoiding care-resistant behaviors during oral hygiene and when assistance is provided with dressing or other activities of daily living; and
  - Strategies for understanding what a resident is communicating and how to respond to his or her needs appropriately.
- Activities. Just like people who live outside of nursing homes, residents need to be involved in activities that are engaging, no matter what their physical or mental abilities may be. Music and art therapy, structured exercise and recreation programs and animal therapy (real or stuffed animals) are some of the activities which have been found to be beneficial.

For more information and resources to help you improve dementia care in your facility please visit www.nursinghome411.org. This website has a section dedicated to Antipsychotic Drugs & Dementia Care with links to resources that we and other organizations have developed to improve care and support your advocacy.
On [www.nursinghome411.org](http://www.nursinghome411.org) we post, approx. every six months data from CMS on all AP drugging – non-risk-adjusted.

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On [www.nursinghome411.org](http://www.nursinghome411.org) we post, approx. every six months, data from CMS on all US nursing homes’ ownership, quality, staffing, resident/family council, penalties, deficiencies, substantiated complaint.

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Resources

- [www.nursinghome411.org](http://www.nursinghome411.org) - Information on a range of nursing home issues with a section dedicated to dementia care and antipsychotic drugs. The website included LTCCC’s reports, consumer guides and information on quality, staffing and antipsychotic drugging for all US nursing homes.

- [www.medicare.gov/nursinghomecompare](http://www.medicare.gov/nursinghomecompare) - The federal website provides information on individual nursing homes nationwide, including their rates of antipsychotic medication use. It also has contact information on State oversight agencies, LTC Ombudsmen and the Federal Nursing Home Complaint Form.

- Sign-up for LTCCC’s quarterly newsletter, *The LTC Journal*, by emailing sara@ltccc.org.

- Join us on Facebook at [www.facebook.com/ltccc](http://www.facebook.com/ltccc).

THANK YOU FOR ATTENDING TODAY’S PROGRAM – I HOPE YOU FOUND IT USEFUL!