Dementia Care Without Drugs II:

What **YOU** Need to Know About Standards of Care and Best Practices for Meeting the Needs of **YOUR** Residents

Richard Mollot, The Long Term Care Community Coalition

www.nursinghome411.org

What is the Long Term Care Community Coalition?

- **LTCCC**: Nonprofit organization dedicated to improving care & quality of life for the elderly & adult disabled in long-term care (LTC).
- **Our focus**: People who live in nursing homes & assisted living.
- **What we do**:
  - Policy analysis and systems advocacy in NYS & nationally;
  - Education of consumers and families, LTC Ombudsmen and other stakeholders.
- **Partners & Members**: LTC Ombudsman Programs, LTC Consumer Advocacy Organizations, the Center for Independence of the Disabled, several Alzheimer's Association Chapters, other senior and disabled organizations. Also individuals, including ombudsmen, who join in our mission to protect residents.
- **Richard Mollot**: Joined LTCCC in 2002. Executive director since 2005.
- **Website**: www.nursinghome411.org.

Today's Program:

- Brief background on the issue: Dementia Care & the Inappropriate Use of Antipsychotic.
- Brief discussion of the relevant standards that support good care.
- Focus: "Behavioral & Psychological Symptoms of Dementia" (BPSD): what they are and what the nursing home should be doing to address them.
- The Dementia Care Advocacy Toolkit.
- Time for discussion, questions and answers.

Alphabet Soup?
A Quick Reference Guide to Some Common Terms

- **Antipsychotic Drugs**: Potent drugs (Haldol, Seroquel, Abilify, etc…) that may have serious side effects. They are indicated to treat conditions such as schizophrenia. They are not generally used for the treatment of symptoms of dementia.

- **BPSD** (Behavioral and Psychological Symptoms of Dementia): Commonly used reference for the verbal and physical expressions associated with dementia, such as signs of distress, agitation, hallucinations and delusions.

- **Non-pharmacological Interventions**: Approaches to dementia care that avoid the use of drugs by focusing on understanding what the individual is experiencing or trying to express and why, and meeting those needs through comforting care and activities appropriate for the individual.

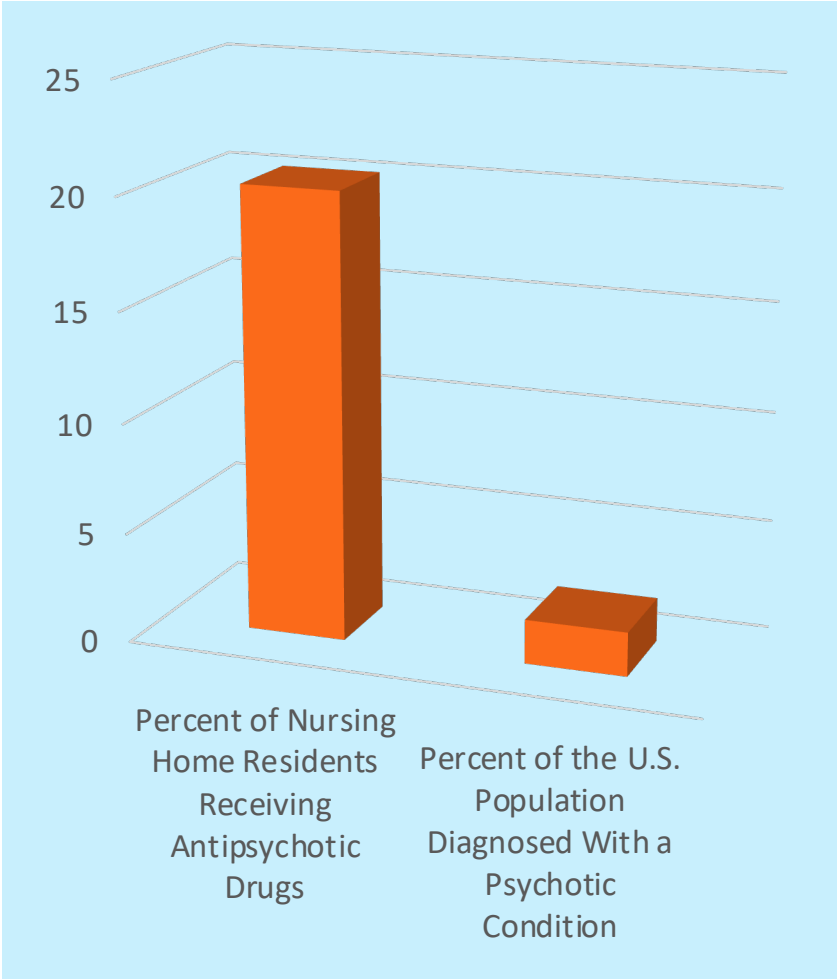
- **CMS** (Centers for Medicare & Medicaid Services): Oversees all licensed nursing home care in the United States.

- **State Survey Agency** CMS contracts with State Agencies to monitor care and enforce nursing home standards. In New York, the agency is **DOH** (NY State Department of Health).

- **MFCU** (Medicaid Fraud Control Unit): Investigates and prosecutes abuse, neglect & fraud. Every state (except North Dakota) has a MFCU.

What is the problem we are trying to address?

- About 20% of our nursing home residents are given powerful antipsychotics. Only about 2% of the population is ever diagnosed with a psychotic condition.
- Over the years, it became a common practice to sedate residents with dementia who are distressed or exhibiting other "behavioral symptoms" of dementia.
- The Food & Drug Administration (FDA) "Black Box" warning states, "Elderly patients with dementia-related psychosis treated with atypical antipsychotic drugs are at an increased risk of death…."
- Antipsychotics commonly have serious side-effects, including: movement disorders, falls, hip fractures, strokes and increased risk of death.
- Antipsychotics stupefy residents and can seriously exacerbate functional and cognitive limitations.
- **Antipsychotic drugs are NOT EFFECTIVE for more than a short period of time in addressing "behavioral symptoms of dementia."**



Important to keep in mind…

The focus of our discussion – and of the federal standards in general – is on nursing home care.

HOWEVER, this is a serious problem for people in assisted living, adult homes and home care too.

A recent study found that:

- 76% of assisted living residents have a documented diagnosis of dementia.
- 37% of those individuals were being given antipsychotic drugs.
- Residents in an assisted living that had a "memory care unit" were more likely to be treated with both dementia medications and antipsychotic drugs.

Why are the laws & regs important?

- The 1987 Nursing Home Reform Law proscribes the use of psychotropic drugs as chemical restraints to control or sedate residents for the convenience of staff.
- In May 2011, the U.S. DHHS Inspector General said **nursing home residents and their families should be "outraged"** by his office's report that well over a quarter of a million residents were receiving antipsychotic drugs for medically unaccepted, off-label uses.
- In a 2012 review of resident records, his office found that 91% did not contain evidence that the resident or the resident's family or legal representative participated in the care planning process. Every resident in this study was administered an antipsychotic drug.
- Recent updates to federal regulations strengthen government expectations for **good dementia care** and **avoiding inappropriate drugging**.

The Nursing Home Reform Law

- Nursing homes are required – and paid – to provide sufficient staff and appropriate services to help residents attain and maintain their highest practicable physical, mental, and psychosocial well-being as individuals. **This includes residents with dementia.**
- Though the the standards are strong, they can only make a difference in the lives of residents if they are ENFORCED.
- Due to lack of enforcement, nursing homes are often poor places to live.
- Our goal is to help YOU achieve this quality of care for YOUR RESIDENTS.

The Law: 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 antipsychotic drugs or other medications unless they benefit the resident. Drugs cannot be given to make things more convenient for staff.

What Can **YOU** Do? What Do **YOU** Need to Know?

The rest of this program will focus on:

- Typical Behaviors that a Person with Dementia Might Exhibit.
- Important Things to Know About "Behavioral & Psychological Symptoms of Dementia."
- The Steps That Care Providers Should Take to Address These Symptoms.
- "Non-Pharmacologic Approaches" - Helping Residents ***Without*** Resorting to Drugs.

You DON'T need to memorize this information!

Just remember **www.nursinghome411.org** for our free Toolkit and other resources.

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.
- Agitation, and/or restlessness.
- Screaming or crying.
- Repetitive motor activity.
- Anxiety and/or Depression.
- Delusions and hallucinations.

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 people.
- **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.

What Steps Should Be Taken to Address BPSD?

- **Obtain details about the person's behaviors** (nature, frequency, severity and duration) and risks of those behaviors, and discuss potential underlying causes with the care team and (to the extent possible) resident, family or representative;
- **Identify potentially remediable causes** of behaviors (such as medical, medication-related, physical, functional, psychosocial, emotional, environmental);
- **Implement non-pharmacological approaches** to care to understand and address behavior as a form of communication and modify the environment and daily routines to meet the person's needs;
- **Implement the care plan consistently** and communicate across shifts and among caregivers and with the resident or family/representative (to the extent possible); ***and***
- **Assess the effects of the approaches**, identify benefits and complications in a timely fashion, involve the attending physician and medical director as appropriate, and adjust treatment accordingly.

What EVERY Provider Should Be Doing.

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.

Non-Pharmacologic Approaches (continued)

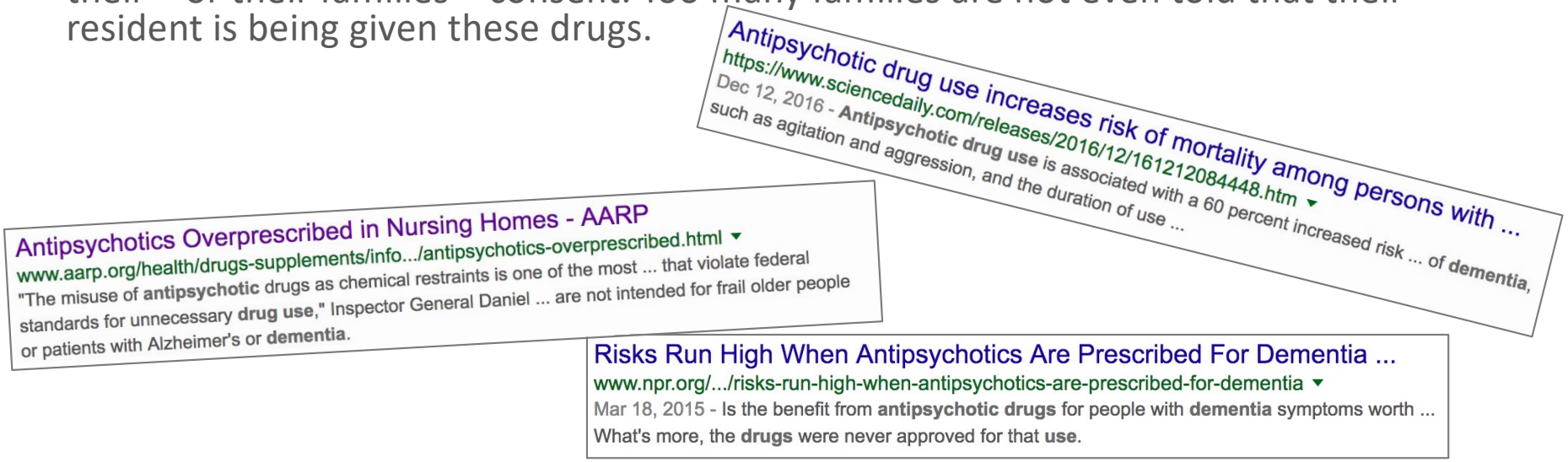
Activities. Just like people who live outside of nursing homes, residents need to be involved in activities that are engaging, no matter what their physical or mental abilities may be. Music and art therapy, structured exercise and recreation programs and animal therapy (real or stuffed animals) are some of the activities which have been found to be beneficial.

The Dementia Care Toolkit – Project Info

- **Purpose**: To engage and educate nursing home families and LTC ombudsmen on some of the issues most relevant to good dementia care and the reduction of inappropriate and dangerous antipsychotic drugging.

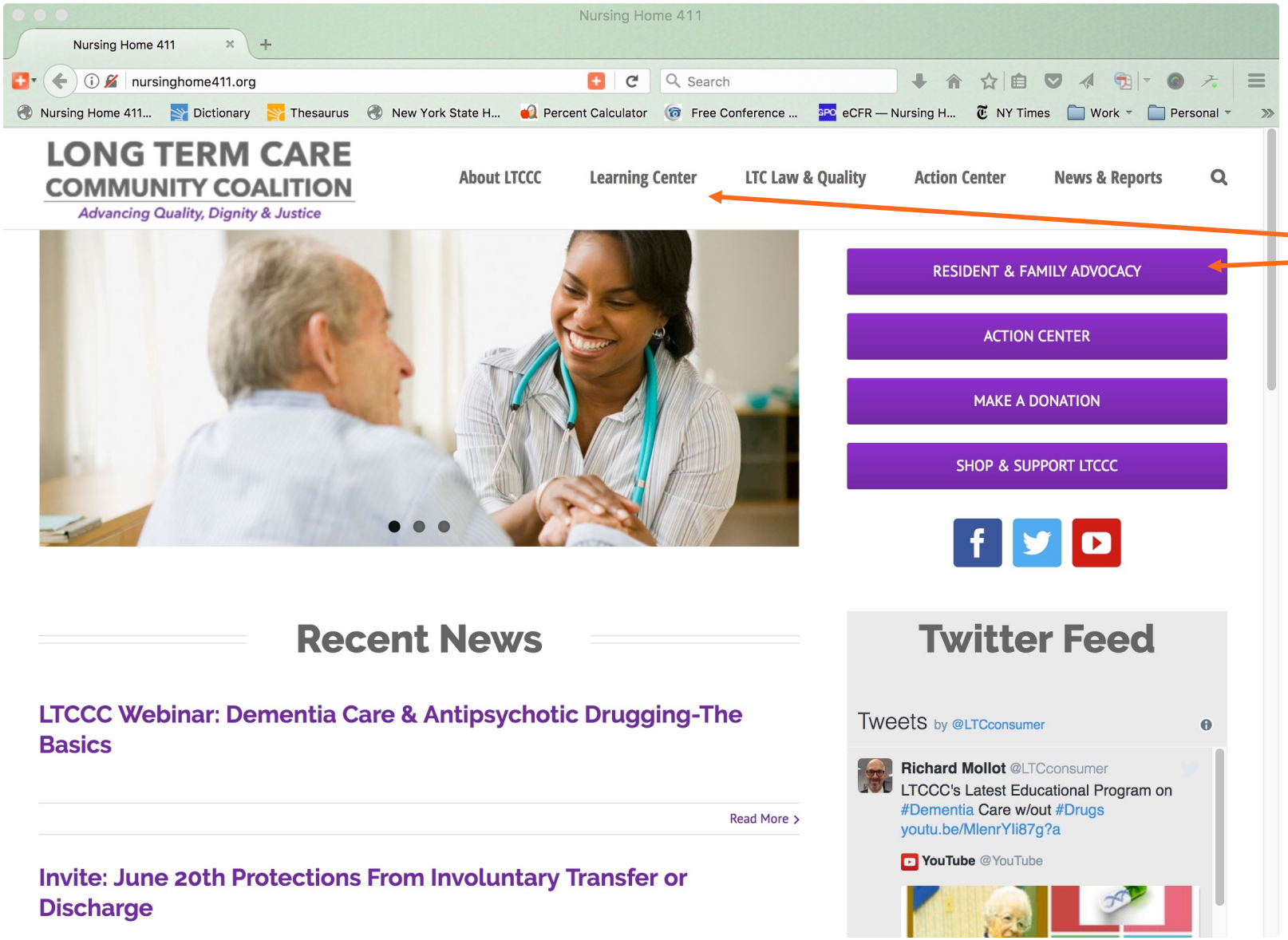
- **How**: LTCCC's executive director attended monthly meetings of two nursing home Family Councils and meetings of the Alliance of NY Family Councils. During each meeting he discussed a relevant dementia care standard and how that standard supported their advocacy for better care and the avoidance of inappropriate drugging.

- **Why**: Too many residents with dementia are given antipsychotic drugs without their – or their families – consent. Too many families are not even told that their resident is being given these drugs.



The project was made possible by the generous support of
The Fan Fox and Leslie R. Samuels Foundation.

The Dementia Care Toolkit at www.nursinghome411.org



There is no need to remember everything.

The resources are available to you whenever you need them.

The Dementia Care Toolkit

What do we have a right to expect **before** drugs are given to a resident?
What do we have a right to expect **after** drugs are given?

LONG TERM CARE COMMUNITY COALITION
Advancing Quality, Dignity & Justice

LTCCC FACTSHEET DEMENTIA CARE & DRUGGING STANDARDS

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. **YOU** can use these standards to support better care in your nursing home.

Below are three standards important to dementia care and the use of psychotropic drugs with information that can be used to support your resident-centered advocacy. [Note: The brackets provide the citation to the relevant federal regulation (CFR) for future reference.]

THE LAW

I. Drug Regimen Review [42 CFR 483.45(c)]

The drug regimen of each resident must be reviewed at least once a month by a licensed pharmacist.

This review must include a review of the resident's medical chart.

The pharmacist must report any irregularities to the attending physician and the facility's medical director and director of nursing, and these reports must be acted upon.

- *Irregularities include, but are not limited to, any drug that meets the criteria set forth in paragraph (d)…* [see "Free from Unnecessary Drugs" below] *for an unnecessary drug.*
- *Any irregularities noted by the pharmacist during this review must be documented on a separate, written report that is sent to the attending physician and the facility's medical director and director of nursing and lists, at a minimum, the resident's name, the relevant drug, and the irregularity the pharmacist identified. The attending physician must document in the resident's medical record that the identified irregularity has been reviewed and what, if any, action has been taken to address it. If there is to be no change in the medication, the attending physician should document his or her rationale in the resident's medical record.*

II. Free from Unnecessary Drugs [42 CFR 483.45(d)]

Each resident's drug regimen must be free from unnecessary drugs. An unnecessary drug is any drug when used-

- In excessive dose (including duplicate drug therapy); or
- For excessive duration; or
- Without adequate monitoring; or
- Without adequate indications for its use; or
- In the presence of adverse consequences which indicate the dose should be reduced or discontinued….

III. Psychotropic Drugs [42 CFR 483.45(e)]

Based on a comprehensive assessment of a resident, the facility must ensure that-

- *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 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.*[1]

BASIC DEMENTIA CARE REQUIREMENTS & EXPECTATIONS

1. Obtain details about the person's behaviors (nature, frequency, severity, and duration) and risks of those behaviors, and discuss potential underlying causes with the care team and (to the extent possible) resident, family or representative;

2. Exclude potentially remediable causes of behaviors (such as medical, medication-related, psychiatric, physical, functional, psychosocial, emotional, environmental) and determined if symptoms were severe, distressing or risky enough to adversely affect the safety of residents;

3. Implement non-pharmacological approaches to care to understand and address behavior as a form of communication and modify the environment and daily routines to meet the person's needs;

4. Implement the care plan consistently and communicated across shifts and among caregivers and with the resident or family/representative (to the extent possible); and

5. Assess the effects of the approaches, identify benefits and complications in a timely fashion, involve the attending physician and medical director (as appropriate for the resident's well-being) and adjust treatment accordingly.

RESOURCES

- WWW.NURSINGHOME411.ORG. LTCCC's website includes materials on the relevant standards for nursing home care, including our Tool-Kit for a listing of antipsychotic drug names and other resources.
- WWW.THECONSUMERVOICE.ORG. The Consumer Voice has numerous materials and resources for residents, family members and LTC Ombudsmen.

[1] There is a limited exception "if the attending physician or prescribing practitioner believes that it is appropriate for the PRN order to be extended beyond 14 days, he or she should document their rationale in the resident's medical record and indicate the duration for the PRN order." PRN orders for anti-psychotic drugs are limited to 14 days and cannot be renewed unless the attending physician or prescribing practitioner evaluates the resident for the appropriateness of that medication.

The Dementia Care Toolkit

What should I look for when assessing a nursing home? What should I see going on in my facility?

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

CONSUMER FACTSHEET: DEMENTIA CARE CONSIDERATIONS

Accessing appropriate care and services for someone with dementia can be daunting. In this fact sheet, we provide some questions to ask and considerations for individuals and families who are faced with making choices about dementia care and advocating for the care and services that are appropriate and beneficial for the individual.

These questions and considerations were adapted from a dementia care survey (inspection) process piloted by the U.S. Centers for Medicare and Medicaid Services. Though they are geared to assessing whether a nursing home is complying with minimum standards, we believe that they can be useful for evaluating whether dementia care is good and appropriate in any setting.

QUESTIONS TO ASK & CONSIDER

- Does the nursing home have specific policies and procedures related to dementia care (whether or not they have a special dementia unit)?
- Do resident care policies and procedures clearly indicate a systematic process for the care of residents with dementia?
- Does the nursing home look systematically at ways to structure the care processes around the residents' individual needs and not around staff needs or routines (including short staffing)?
- Does the overall philosophy of care in the nursing home acknowledge behaviors as a form of communication?
- Is that philosophy evidenced in the care practices in the facility? How?
- Are care staff actively trying to understand the meaning behind dementia-related behaviors and responding in a way that is appropriate and beneficial to the resident?
- Is it evident, through conversations with facility staff and leadership, that nationally recognized dementia care guidelines or programs (for examples see the document *NonPharma Approaches to Dementia Care* on www.nursinghome411.org) are the basis of care for people with dementia in the nursing home?
- Do resident care policies and procedures clearly outline a systematic process for the care of residents with dementia?
- Are staff receiving dementia care training? If so, what kind and how often?

PRACTICES TO OBSERVE & CONSIDER

- **Observe** for language or routines that could have an impact on dignity and/or function, e.g.:
  - Use of bibs;
  - High percentage of residents wearing socks/non-skid socks and institutional gowns instead of their own clothes and shoes;
  - Residents with soiled hands or nails, unshaven or with hair not combed;
  - Failure to respond to residents' communication/behavioral manifestations of distress/emotional to prevent escalation of distress; and
  - Attempts to keep residents "quiet" or prevent them from moving around versus efforts to walk or talk with residents who appear distressed.
- **Observe** for social dining atmosphere or individualized dining setting (as appropriate) with staff sharing the dining experience with residents (not standing over them).
- **Observe** for staff talking with residents, not talking only with other staff or ignoring residents. Observe for culturally appropriate meals.
- **Observe** for whether or not staff assesses the environment regularly for too much or too little noise, light and stimulation. (Since this may be difficult to ascertain during observations alone, speak with staff about how they address environmental issues for individuals with dementia).
- **Observe** for other basic dementia care approaches such as:
  - Using soft, low voice and speaking where resident may read lips/see face clearly;
  - Not approaching resident from behind;
  - Providing adequate time during resident care and meals (not rushing);
  - Encouraging maximal independence (not performing activities/care routines that resident could perform him/herself if given adequate time and cues);
  - Encouraging time outdoors and resident involvement in physical activities;
  - Redirecting resident away from high stress environments;
  - Allowing a resident to remain in preferred location (e.g., to remain in bed) if safe, and re-approaching that resident later on if they express a desire/choose to remain where they are (staff recognizing this as preference/choice, even in someone who has dementia);
  - Providing stimulation (to avoid boredom);
  - Ensuring an adequate number and type of activities on all shifts, including weekends;
  - Addressing loneliness/isolation; and
  - Appropriately limiting choices to avoid frustration/confusion.
- **Assess** for adequate sleep and individualized sleep hygiene in care plan (sleep facilitators, such as reducing interruptions for continence care or pressure relief through use of appropriate continence products and mattresses); sleep log or diary if indicated. Assess for residents sleeping often during activities.
- **Evaluate** for adequate pain assessment in all residents with particular attention to those with difficulty communicating about pain.
- **Assess** for issues during care transitions. For example, was there a unit or room change? What prompted this change? How was information transferred effectively among care providers.

RESOURCES

- WWW.NURSINGHOME411.ORG. LTCCC's website includes materials on the relevant standards for nursing home care, a listing of antipsychotic drug names and other resources.
- WWW.THECONSUMERVOICE.ORG. The Consumer Voice has numerous materials and resources for residents, family members and LTC Ombudsmen.

The Dementia Care Toolkit

How does a facility plan for a resident's care? How can I make sure that my resident's needs are identified and addressed by my nursing home?

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

CONSUMER FACTSHEET: 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. YOU can use these standards as a basis for advocating in your nursing home.
Following are two important standards for residents assessment and 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.]

I. 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:*
  - ✓ Identification and demographic information.
  - ✓ *Customary routine.*
  - ✓ *Cognitive patterns.*
  - ✓ *Communication.*
  - ✓ *Vision.*
  - ✓ *Mood and behavior patterns.*
  - ✓ *Psychosocial well-being.*
  - ✓ *Physical functioning and structural problems.*
  - ✓ *Continence.*
  - ✓ *Disease diagnoses and health conditions.*
  - ✓ *Dental and nutritional status.*
  - ✓ *Skin condition.*
  - ✓ *Activity pursuit.*
  - ✓ *Medications.*
  - ✓ *Special treatments and procedures.*
  - ✓ *Discharge planning.*
  - ✓ *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.*

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

II. COMPREHENSIVE PERSON-CENTERED CARE PLANNING [42 CFR 483.21]

The facility must develop and implement a comprehensive person-centered care plan for each resident, consistent with… resident rights…, that includes measurable objectives and timeframes to meet a resident's medical, nursing, and mental and psychosocial needs that are identified in the comprehensive assessment. The comprehensive care plan must describe the following:

- *The services that are to be furnished to attain or maintain the resident's highest practicable physical, mental, and psychosocial well-being…*
- *Any services that would otherwise be required… but are not provided due to the resident's exercise of rights…, including the right to refuse treatment…*
- *In consultation with the resident and the resident's representative(s)—*
  - *The resident's goals for admission and desired outcomes.*
  - *The resident's preference and potential for future discharge. Facilities must document whether the resident's desire to return to the community was assessed and any referrals to local contact agencies and/or other appropriate entities, for this purpose.*
  - *Discharge plans in the comprehensive care plan, as appropriate…*

A comprehensive care plan must be…Developed within 7 days after completion of the comprehensive assessment.

IMPORTANT NOTE: The new federal nursing home standards greatly expanded expectations for care planning. See the "LTCCC Factsheet Care Planning Requirements" for important details on how care plans must be developed and carried out.

BASIC CONSIDERATION TO KEEP IN MIND

- 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 or staffing levels 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, training materials and other resources.

The Dementia Care Toolkit

- Introduction to the Toolkit
- Dementia Car 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 Recordkeeping
- Standards for People Providing Care
- Standards for Nursing Home Services
- Standard of Care to Ensure Resident Wellbeing


Questions?
Comments?

Thank You For Joining Us Today!

Email **info@ltccc.org** or call **212-385-0355** if you would like to…

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- Sign up for our newsletter and alerts.

You can also…

- Join us on **Facebook** at www.facebook.com/ltccc
- Follow us on **Twitter** at www.twitter.com/LTCconsumer
- Visit us on the **Web** at www.nursinghome411.org.

For LTC Ombudsmen in NY State

If you would like us to let your supervisor know that you attended this training program, please take the quick survey at:
https://www.surveymonkey.com/r/ltccc-ltcop1

For Family Members in NY State

connect with the Alliance of NY Family Councils at **www.anyfc.org** (or email info@anyfc.org).

+ Coming Up

The New Nursing Home Regulations: Protections From Involuntary Discharge or Transfer: June 20 at 1pm

We will also be webcasting our LTC Ombudsman training program, Introduction to Nursing Home Oversight and the New Regulations, on June 14 from 11am – 1pm.

Attend Any LTCCC Program in Two Easy Ways:

1) To join the online meeting, about five minutes before the scheduled time of the meeting, go to the link below and follow the prompts to join the meeting.

Online Meeting Link: **https://join.freeconferencecall.com/richardmollot**.

2) To participate by phone, at the scheduled time of the meeting call (712) 770-4010. When prompted, enter the Access Code, 878277, followed by the pound (#) key. Press *6 to mute or unmute your phone line.

If you would like to receive a copy of the webinar handouts, please email sara@ltccc.org (noting the date of the program).