



# Dementia Care Without Drugs I: The Basics

Presented by Richard Mollot, Long Term Care Community Coalition

[www.nursinghome411.org](http://www.nursinghome411.org)

## + What is the Long Term Care Community Coalition?

2

- **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.
- **Coalition members** include several LTC Ombudsman Programs, the Center for Independence of the Disabled, AARP NY, 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.



# + What Will We Be Talking About?

3

## TODAY: Dementia Care & Antipsychotic Drugging

- Why is it a problem?
- How often does it happen?
- What is being done about it?
- What does the law say?

May 26  
1pm

## Next Week: A Deeper Dive

- Appropriate care practices for residents with dementia (including non-drugging approaches to address so-called dementia “behaviors”)
- Advocacy tips & resources for resident-centered advocacy.

## + Dementia

4

- Dementia, and dementia care, is a growing concern for individuals and families as our population ages and more people live longer with Alzheimer's and other forms of dementia.
- According to the Alzheimer's Association, 10% of people age 65+ are living with Alzheimer's Disease (the most frequently occurring, but not only, type of dementia).
- Some common "behavioral symptoms" of dementia:

Restlessness

Wandering

Agitation

Aggression

## + Dementia

- Our understanding of dementia, of the experiences of people living with dementia and of their behavioral symptoms, continues to evolve.
- As a result, acceptable care practices and treatment of people with dementia have also evolved.



## + What is the problem we are trying to address?

6

- Almost one in five of our nursing home residents are given powerful antipsychotics every day. Only about 2% of the population is ever diagnosed with a psychotic condition recognized by CMS.
- 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.”**







## 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 Dept of Health).
- **MFCU** (Medicaid Fraud Control Unit): Investigates and prosecutes abuse, neglect & fraud. Every state (except North Dakota) has a MFCU.
- **OMIG** (Office of the Medicaid Inspector General): State office which audits providers & imposes sanctions for Medicaid fraud.



# 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 unacceptable, 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**.





## How did this problem happen?

- Drug companies marketed these drugs widely, and illegally, as a way to provide care for people with dementia and as appropriate “treatment” for behaviors associated with dementia.
- Lack of:
  - 1) sufficient provider training,
  - 2) sufficient staffing and
  - 3) government enforcement of dementia care standards.



# + The Federal Campaign

Goal: Improve Dementia Care & Reduce the Use of Antipsychotic Drugs

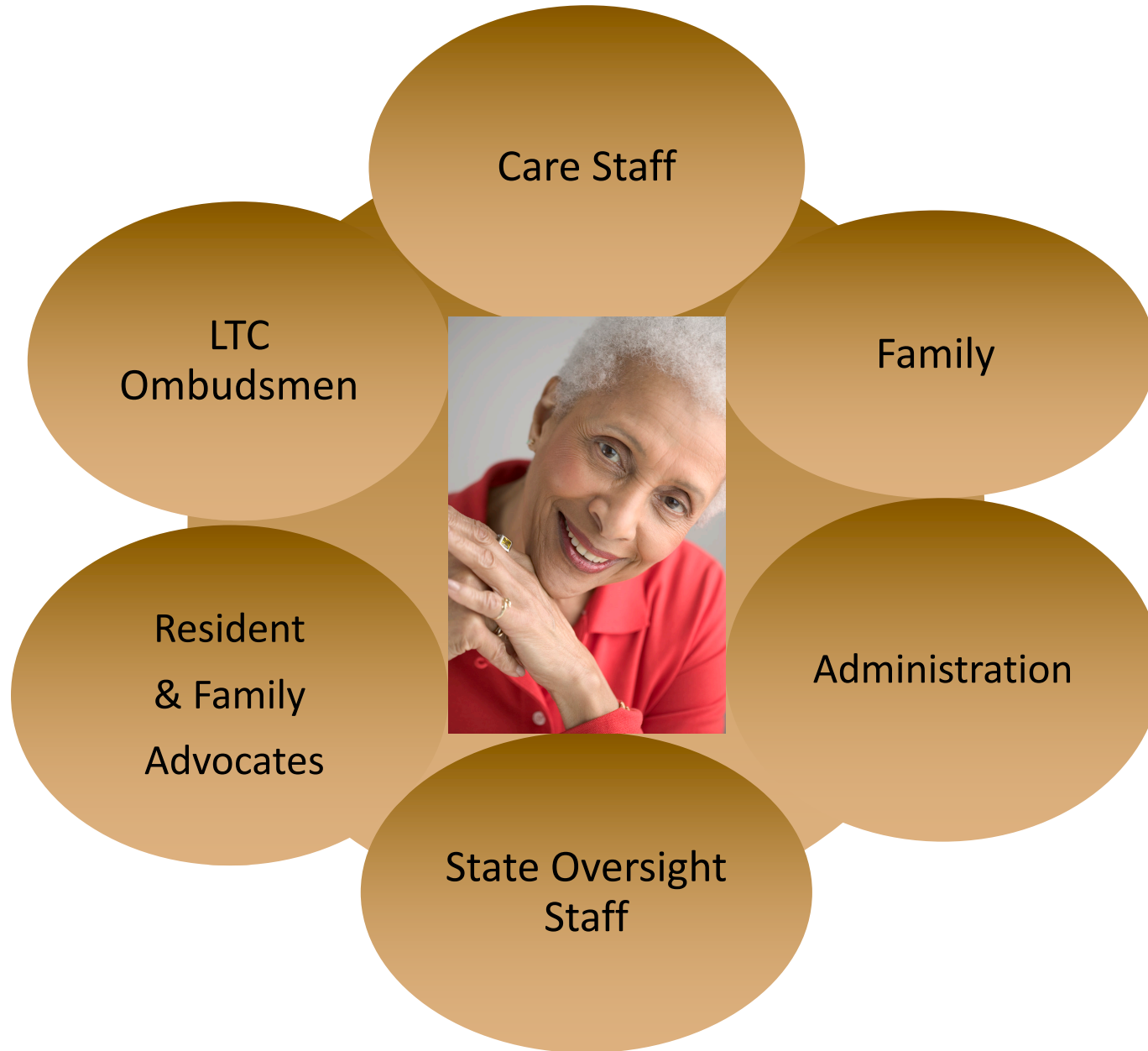
- CMS initiated a campaign to reduce antipsychotic drugging in March 2013, setting a national goal of 15% reduction in antipsychotic drugging by December of that year.
- LTCCC wrote consumer guide for CMS: ***Get the Facts about Antipsychotic Drugs & Dementia Care.***
- **Education:** Nursing homes now required to conduct annual trainings on good dementia care practices for their caregivers.
- **Oversight:** CMS & the State are supposed to be increasing surveyor focus on good dementia care and avoidance of unnecessary drugs.
- **Unfortunately**, the above goal was not met until the end of 2013 – a full year later!
- Little has been done to increase – or maintain – momentum since.
- This is why it is important for **US** to know our rights and work to achieve them, because...

Remember: All of the standards we are talking about today have been part of the law for over 25 years!



# Everyone Has a Role in Quality Care

11



## + 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.

This problem affects people with dementia in ALL settings.

# + The Law: Residents' Rights

ALL of the rights we are talking about today have been in place since 1991, under the US Nursing Home Reform Law.

13

- **Informed Decision-Making:** Residents have the right to be informed about the risks and benefits of any medication.
- **Right to Refuse:** Residents have the right to refuse a medication.
- **Freedom from Chemical Restraints:** It is against the law to give medications that do not benefit the resident, such as for convenience of staff.

# + The Law: Informed Consent

The resident has the right to...

- Participate in planning care and treatment.
- Be fully informed in language that he or she can understand of his or her total health status.
- Be informed, in advance, of the care to be furnished and the type of caregiver or professional that will furnish care.
- Be fully informed of any proposed changes in care or treatment that may affect the resident's well-being.
- Be informed in advance, by the physician or other practitioner, of the risks and benefits of proposed care, of treatment alternatives and treatment options and to choose the alternative or option he or she prefers.
- Refuse treatment (regardless of whether doing so may be detrimental).

**How does this apply to residents with dementia?** If a resident is judged incompetent under the laws of the state, "the rights of the resident are exercised by the person appointed under State law to act on the resident's behalf."



*"Informed consent is an ethical concept—that all patients should understand and agree to the potential consequences of their care."*

# + Informed Consent Checklist

## CHECKLIST FOR RESIDENTS, FAMILIES & OMBUDSMEN

The physician/prescriber (not a delegated representative) should disclose and discuss:

- ✓ The diagnosis, if known
- ✓ The nature and purpose of a proposed treatment or procedure
- ✓ The risks and benefits of proposed treatment or procedures
- ✓ Alternatives (regardless of costs or extent covered by insurance)
- ✓ The risks and benefits of alternatives
- ✓ The risks and benefits of not receiving treatments or undergoing procedures

This checklist is from LTCCC's "Informed Consent" factsheet. All of our factsheets are available for free at [www.nursinghome411.org](http://www.nursinghome411.org)



## + The Law: Drug Regimen Review

- *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.*

Federal  
requirements  
for nursing  
homes.

## + The Law: Drug Regimen Review

- Irregularities include, but are not limited to, any drug that meets the criteria for an unnecessary drug.
- Any irregularities noted by the pharmacist during this review must be documented on a separate, written report.
- The written report must be sent to the attending physician and the facility's medical director and director of nursing.
- The report must list, 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.

### Drug Irregularities

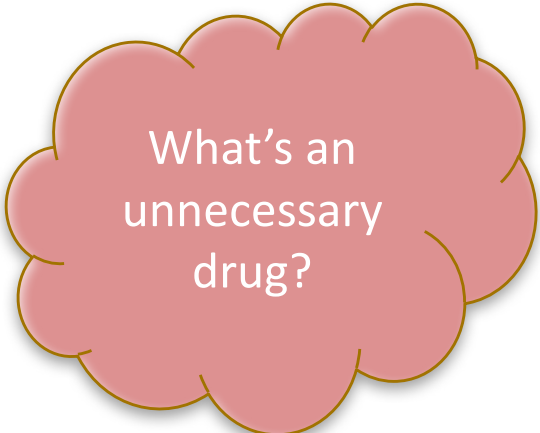
1. What are they?
2. What must be done about them?

## + The Law: Free from Unnecessary Drugs

*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.*



What's an unnecessary drug?

## + The Law: Psychotropic Drugs

*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. [With ltd exceptions.]*

Additional  
requirements  
for  
psychotropic  
drugs





# Resources

## LONG TERM CARE COMMUNITY COALITION

*Advancing Quality, Dignity & Justice*

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

This factsheet focuses on the “Behavioral & Psychological Symptoms of Dementia” (BPSD): what they are and what nursing homes should be doing to address them. You can use this information to support better understanding and care.

Note: While our [factsheets](#) focus on standards for nursing home, we believe that good practices are universal and that these standards are relevant to no matter where the individual with dementia lives.

#### 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 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.

## LONG TERM CARE COMMUNITY COALITION

*Advancing Quality, Dignity & Justice*

### CONSUMER FACTSHEET: INFORMED CONSENT

The right to informed consent is an important one for residents and families to know about (it is hard to exercise informed consent if you don’t know you have a right to it!). It is also one of the most important standards related to dementia care and the widespread problem of inappropriate antipsychotic drugging.

Please note: (1) Text in italics is directly from the federal regulations. (2) Numbers in brackets [42 CFR 483.xx] refer to the provision in the federal regulations and are provided for reference. (3) These standards are applicable to all residents in licensed nursing homes in the United States, whether they are short-term or long-term, private pay, Medicaid, Medicare or have another type of insurance. (4) Where the resident lacks capacity to make decisions and/or has assigned decision-making to someone else, that person takes the place of the resident in exercising these rights.

#### WHAT IS INFORMED CONSENT?

“Informed consent is an ethical concept—that all patients should understand and agree to the potential consequences of their care—that has become codified in the law and in daily practice at every medical institution.” [ From [A Practical Guide to Informed Consent](#).]

#### THE LAW

#### I. Right to be Informed of & Participate in Treatment Plan [42 CFR 483.10(c)]

*The resident has the right to be informed of, and participate in, his or her treatment, including:*

- *The right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition.*
- *The right to be informed, in advance, of the care to be furnished and the type of care giver or professional that will furnish care.*
- *The right to be informed in advance, by the physician or other practitioner or professional, of the risks and benefits of proposed care, of treatment and treatment alternatives or treatment options and to choose the alternative or option he or she prefers.*

#### II. Right to Participate in Development & Implementation of Care Plan [42 CFR 483.10(c)]

- *The right to participate in the planning process, including the right to identify individuals or roles to be included in the planning process, the right to request meetings and the right to request revisions to the person-centered plan of care.*

## + Coming Up

22

### **Dementia Care Without Drugs Part II: May 26**

- Appropriate care practices for residents with dementia (including non-drugging approaches to address so-called dementia “behaviors”)
- Advocacy tips & resources for Families, LTC Ombudsmen and other Resident Advocates.
- The Dementia Care Advocacy Toolkit.

### **The New Nursing Home Regulations: Protections From Involuntary Discharge or Transfer: June 20**

**All Programs Start  
@ 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](mailto:sara@ltccc.org) (noting the date of the program).



## + Our Goal: To Provide **You** With **Knowledge** and **Resources** to Support Your Resident-Centered Advocacy

### ■ **Knowledge...**

- **Free monthly training programs** for Resident & Family Councils, LTC Ombudsmen and those who work with them.
- Each program will focus on a nursing home standard that is relevant to resident care, dignity or quality of life.

### ■ **Resources...**

- **[WWW.NURSINGHOME411.ORG](http://WWW.NURSINGHOME411.ORG)** has a **Learning Center for Residents, Families, Ombudsmen** and those who work with them.
- For every standard we will post a **free handout** on our website that you can use now and in the future to know your rights about a specific issue or standard.
- **Presentation materials** will be posted on the website after each program for future reference.
- **Technical support for your questions** or concerns on the quality standards via our NYS List-serve and email. Email [info@ltccc.org](mailto:info@ltccc.org).

**You DON'T need to memorize every Resident Right!**  
Just remember **[www.nursinghome411.org](http://www.nursinghome411.org)** for free info & resources.



# Thank You For Joining Us Today!

24

Email [info@ltccc.org](mailto:info@ltccc.org) or call **212-385-0355** if you would like to...

- Receive alerts for future programs or
- Sign up for our newsletter and alerts.

You can also...

- Join us on **Facebook** at [www.facebook.com/ltccc](http://www.facebook.com/ltccc)
- Follow us on **Twitter** at [www.twitter.com/LTCconsumer](http://www.twitter.com/LTCconsumer)
- Visit us on the **Web** at [www.nursinghome411.org](http://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](http://www.anyfc.org) (or email [info@anyfc.org](mailto:info@anyfc.org)).