



The NEW Nursing Home Regulations

Decisions About Care, Participation in Care Planning & Informed Consent

Presented by Richard Mollot, Long Term Care Community Coalition

www.nursinghome411.org

This program is made possible by the generous support of the NY State Health Foundation

+ 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.
- **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 TODAY?

1. Brief Background on the Nursing Home System:
The Law & Regulatory Standards
2. Resident Rights:
Care Planning, Choice & Consent Under the New Regs



Resident Rights

Law

Regulation

Oversight

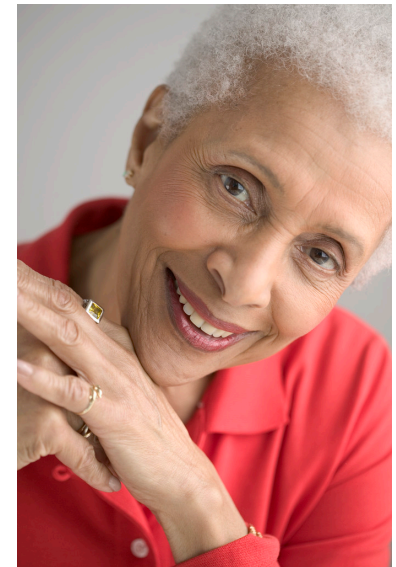
+ The Nursing Home System in a Nutshell

- Virtually all nursing homes participate in Medicaid and/or Medicare.
- In order to participate in Medicaid/Medicare, a facility agrees to meet the standards provided for in the federal **Nursing Home Reform Law**.
- States may have *additional* protections, but no state can have less protections.
- Federal *protections are for all the residents* in a facility, whether their care is paid for by Medicare, Medicaid or private pay.
- The federal agency, CMS, contracts with the state DOH to ensure that residents are protected and receive the services they need and deserve.



+ The Nursing Home Reform Law

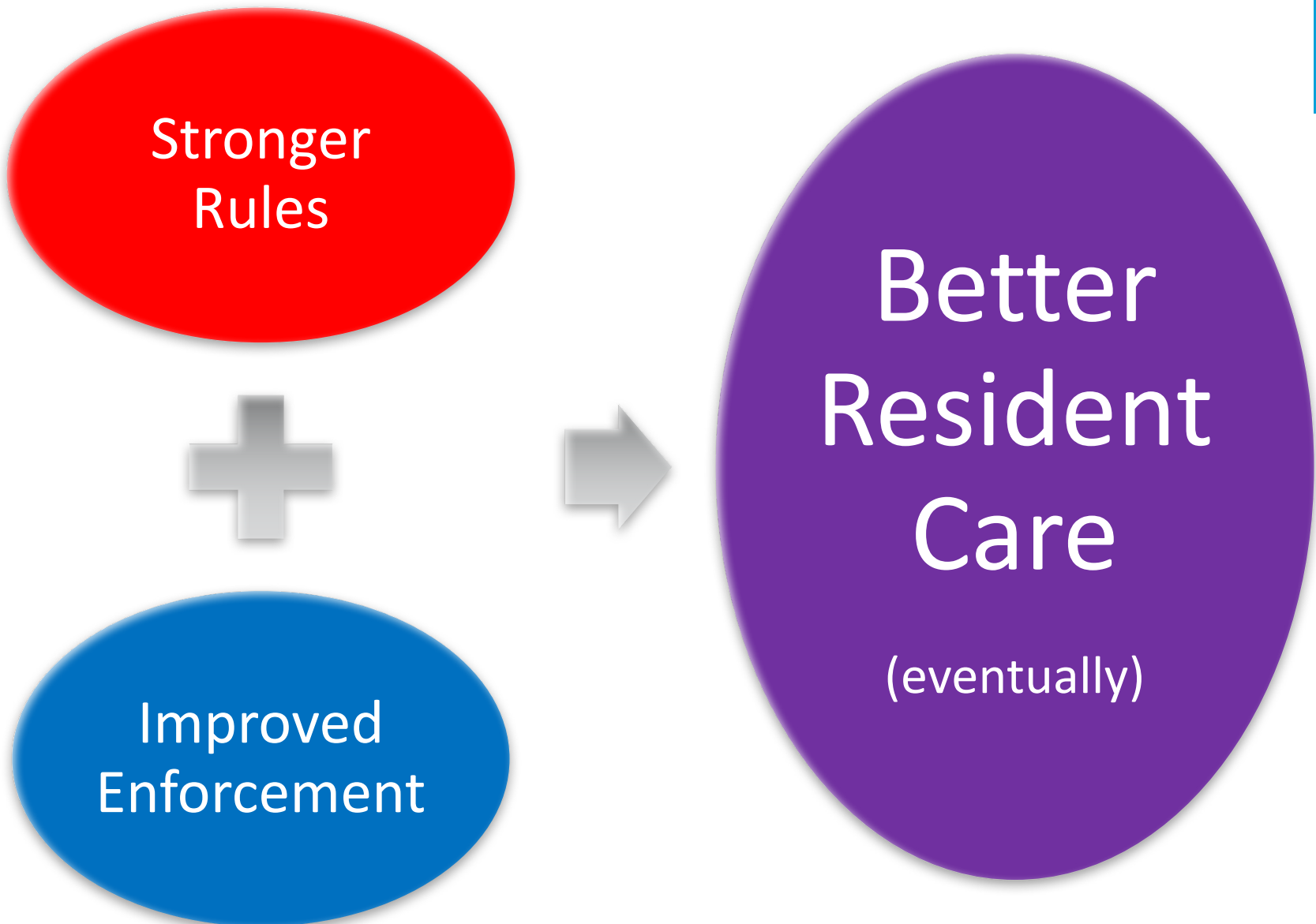
- The federal law requires that every nursing home resident is provided the care and quality of life services sufficient to attain and maintain her **highest practicable physical, emotional & social well-being**.
- The law emphasizes **individualized, patient-centered care**.
- Importantly, the law lays out specific resident rights, from **good care** and monitoring to a quality of life that maximizes **choice, dignity & autonomy**.
- The law passed in 1987. Regulatory standards came out in 1991.



+ What is Happening Now?

- For the first time in 25 years, the federal regulatory system has been significantly revised and updated.
- This will affect **every aspect of care & quality of life.**
- **All of the Regulations are changing.** For 25 years everyone – nursing homes, surveyors, ombudsmen and advocates – knew what the rules were and where to find them. That entire structure has changed.
- **All of the Guidelines are changing.** The guidelines detail what is expected of nursing homes in relation to each standard – what they are supposed to do and how they are suppose to do it.
- **The F-tag system, used by nursing home inspectors, is changing.** When a surveyor identifies a problem in care or living conditions in a nursing home, she cites the nursing home using a system called “F-tags” – numbers that correlate with the regulatory requirements.

+ Why Does it Matter?



+ What Does This Mean For Us?

Now more than ever....

We **MUST** be aware of
what our rights are, and
what we have a right to
expect from our nursing
homes.



Resident Rights:

- ✓ Care Planning
- ✓ Informed Consent
- ✓ Right to Decide (Including Refuse) Treatment

+ Care Planning

§483.10(c) *Planning and Implementing Care.*

- 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.*

Orange
Type
=
New
Regulatory
Language

+ What is Total Health Status?

According to federal regulations, “Total Health Status” includes...

- *Functional status,*
- *Nutritional status,*
- *Rehabilitation and restorative potential,*
- *Ability to participate in activities,*
- *Cognitive status,*
- *Oral health status,*
- *Psychosocial status, and*
- *Sensory and physical impairments.*

What Does It Mean?

“The right to be fully informed in language that he or she can understand of his or her total health status.”

To Whom Does It Apply?

1. The resident.
2. The resident’s designated representative.

+ Informed Consent

■ **What does it mean?** Every patient should:

1. Understand the risks and benefits of proposed care services or medication, as well as possible alternatives;
2. Have the opportunity to say yes or no; and
3. Choose the alternative or option that the patient prefers.

■ **Why is it important?**

1. General: The locus of decision-making is the resident.
2. Antipsychotic drugging: The resident (or her representative) must be fully informed in advance of the use of drugs, understand and be involved in planning and implementation of the care plan (which should include plans to reduce drugs and implement non-pharmacological approaches) and has the right to say no.

+ Informed Consent

- **What can YOU do?** Ask to speak to the physician (or prescribing practitioner) directly about:
 - The diagnosis;
 - The nature and purpose of proposed treatment, procedure or medication;
 - The risks and benefits;
 - The alternatives (regardless of costs or extent covered by insurance);
 - The risks and benefits of alternatives; and
 - The risks and benefits of not receiving treatments or undergoing procedures.



+ Informed Consent: **Scenario**

Mrs. Darcy's son, Jim, comes to visit her once a week. When Jim leaves, she often seems very sad. Lately, as her dementia has progressed, Mrs. Darcy has started to become very confused and upset when Jim gets up to go: crying, sometimes even screaming and striking out at aides when they take her back to her room.

The nursing home staff have approached Jim and said that her behavior is disturbing to other residents and something needs to be done for her sake as well as that of other residents. She can't be lashing out at her caregivers. The head nurse said they need to give Mrs. Darcy a medication, Haldol, to calm her down before she hurts herself or someone else.

What can Jim do?

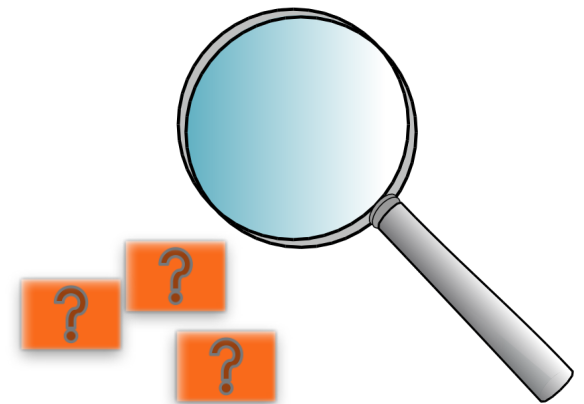
+ What Jim Can Do:

1. **Ask to Speak Personally to the Doctor (prescribing practitioner)**

- What is Haldol?
- What is it supposed to accomplish?
- What are potential side effects and dangers, for both short and long term?
- What are the alternatives?
- If consent is given, what are the plans for monitoring Mrs. Darcy to ensure that side effects are avoided/minimized and that the treatment continues to be beneficial to her?
- When can we schedule the next care-planning meeting to discuss how Mrs. Darcy is doing?

2. **Do Independent Research**

- Search on-line and speak to the LTC Ombudsman.
- Use the questions above as your guide.
- Take notes or print out information for future reference.
- Visit the Learning Center on www.nursinghome411.org for helpful resources.





Resources @ www.nursinghome411.org

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. This page provides the major points from the federal regulations. The next page provides tips on what YOU can do to advocate for better care.

STANDARD 1: PHARMACY SERVICES¹ [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 SERVICES² [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.

¹ Formerly Free From Unnecessary Drugs [F-329 - 42 CFR 483.25(i)(2)(i, ii)]. 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].

ANTIPSYCHOTICS BY CLASS – AS OF DECEMBER 2015

Generic name	Brand names
	<u>typical antipsychotics</u>
Acepromazine	Atravet, Acezine
Acetophenazine	Tindal
Benperidol	Frenactyl
Bromperidol	Bromidol, Bromodol
Butaperazine	Repoise, Tyrylen
Carfenazine	
Chlorproethazine	
Chlorpromazine	Largactil, Thorazine
Chlorprothixene	Clozan, Taractan, Truxal
Clopenthixol	Sordinol
Cyamemazine	Tercian
Dixyrazine	Esucos
Droperidol	Droleptan, Dridol, Inapsine, Xomolix, Innovar (+ Fentanyl)
Fluanisone	
Flupentixol	Depixol, Fluanxol
Fluphenazine	Prolixin, Modocate
Fluspirilene	Redeptin, Imap
Haloperidol	Haldol
Levomopromazine	Nosinan, Nozinan, Levoprome
Lenperone	Elanone-V
Loxapine	Loxapac, Loxitane
Mesoridazine	Serentil
Metitepine	
Molindone	Moban
Moperone	Luvatren
Oxypertine	Equipertine, Forit, Integrin, Lanturil, Lotawin, Opertil
Penfluridol	Semap, Micefal, Longoperidol
Perazine	Taxilan
Periciazine	Neuleptil, Neulactil
Perphenazine	Trilafon
Pimozide	Orap
Pipamperone	Dipiperon, Dipiperol, Piperonil, Piperonyl, Propitan
Piperacetazine	Quide
Pipotiazine	Piportil
Prochlorperazine	Compazine, Stemizine, Buccastem, Stemetil, Phenotil
Promazine	Sparine
Prothipendyl	
Spiroperone	Spiroperidol, Spiropitan
Sulfuridazine	Imagotan, Psychoson, Inofal

Visit <http://www.nursinghome411.org/> for more information on antipsychotic drugs and dementia care.

+ Recap

- Residents and their representative(s) must be afforded the opportunity to participate in their care planning process and to be informed in advance about decisions and changes in care, treatment and/or interventions.
- This applies both to initial decisions about care and treatment, the right to modify one's choice after the initial decision and the right to refuse care or treatment.
- Facility staff **must** support and encourage participation in the care planning process.

+ Recap

- The resident's designated representative takes the place of the resident in being informed about care and acting in the resident's best interests.
- The right to be informed, participate in care planning and say "no" = the right to *Informed Consent* to care and treatment.
- There are many resources @ www.nursinghome411.org and elsewhere to help you when you are faced with care challenges.



Questions?

Comments?

+ 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** 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.

You DON'T need to memorize every Resident Right!
Just remember www.nursinghome411.org for free info & resources.

+ Coming Up

Next Program: May 16th at 1pm.

Topics: Resident's Rights...

- **A safe environment;**
- **Resident and family councils;**
- **Grievance processes.**



**Remember...
We Can't
Fight For Our
Rights If We
Don't Know
What They
Are.**



Thank You For Joining Us Today!

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

- Receive the advocacy fact sheet for this program;
- Receive alerts for future programs;
- Sign up for our newsletter and action alerts; or
- Join our list-serve community, open only to residents, families, LTC Ombudsmen and advocates in NY State.

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.

We encourage family members to connect with the Alliance of NY Family Councils at www.anyfc.org (or email info@anyfc.org).



Thank you to the New York State Health Foundation for supporting these programs!