Making Your Voice Heard in the Nursing Home... and Beyond

Presented by Richard Mollot, Long Term Care Community Coalition

www.nursinghome411.org
About 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;  
  - Home of the local LTC Ombudsman Program for the Hudson Valley, New York.

What Will We Be Talking About TODAY?

- **BRIEF BACKGROUND**
  - The Federal Nursing Home Law
  - Residents’ Rights to Good Care & Safety

- **MAKING YOUR VOICE HEARD...**
  - In the Nursing Home
  - Outside of the Nursing Home

**Note:** Today’s program will discuss tools that you can use to support resident-centered advocacy. While these tools can be useful when filing a complaint against a nursing home with a state agency, law enforcement, or a personal attorney, we will not be specifically discussing how to file such a complaint today. Reporting problems and filing complaints will be covered in a separate program in March.
The Nursing Home Reform Law

The Nursing Home Reform Law (aka OBRA 87) requires that every nursing home resident is provided the care and quality of life services sufficient to attain and maintain his or her highest practicable physical, emotional, and psycho-social well-being.

This is what we pay for.

This is what providers agree to provide.

This is what every resident deserves.
The Nursing Home Reform Law

- Emphasis on individualized, resident-centered care – to reduce problems, including abuse and neglect, and ensure that residents are treated with dignity and have a good quality of life.

- The law lays out specific resident rights, from good care and monitoring to a quality of life that maximizes choice, dignity and autonomy.
Unfortunately, too many residents are subjected to neglect, substandard care, abuse...

- The majority of nursing homes have less staffing than federal studies have indicated as necessary to meet residents’ basic needs.

- Antipsychotic drugging, a major problem, continues to be pervasive.

- Thousands of residents suffer with pressure ulcers every day.

- 2014 federal study found that 1/3 of short-term, rehab residents are harmed within about two weeks of entering the nursing home. 59% of that harm was avoidable.
While many facilities provide good care and life with dignity for their residents, in the absence of meaningful enforcement of minimum standards, too many facilities will skimp on staffing and services to increase profits.
Making Your Voice Heard...
In the Nursing Home
A Few Pointers....

- **Be polite.** Most people want to do a good job. Nobody likes to be attacked, or feel badly about the job they are doing. Though it is upsetting to be receiving poor care, or to see a loved one suffer, it is important to remember our goal: to improve care or conditions for the resident.

- **Know your rights.** See LTCCC’s Learning Center for helpful fact sheets and other resources.

- **Work together (whenever possible).**
  1. Facility staff. Try to work cooperatively with staff. “These are my rights... how can we make it happen?”
  2. Join the resident or family council.

- **Keep good records.** It can be very hard to keep track of a concern or complaint, especially in a confusing or stressful situation. To help, LTCCC is putting together free, easy-to-use tools.
Who to Speak to….

- **Start with those working closest to resident and work out from there.** If a problem can be resolved with the cooperation of caregivers, great!
- **Grievance officer.** Every nursing home is now required to have a grievance officer who is responsible for taking complaints, leading any necessary investigations, and tracking them through to conclusion. Residents and their representatives have a right to a written decision.
- **LTC ombudsman.** The LTC ombudsman can help you to navigate and resolve problems. If your facility does not have a regular ombudsman visiting, you can contact the LTC Ombudsman office.
- **Resident & family councils.** As noted above (and throughout our resources) participating in a resident or family council can be a very effective vehicle for raising concerns about care or quality of life in your facility in a constructive way.

**Important Note:** These are some general suggestions. It is important, however, to always act in the best interest of the safety of residents, staff, and visitors.
Family & Ombudsman Resource Center

Welcome to our dedicated Family & LTC Ombudsman page. We will be updating it frequently with resources and tools that you can use to support your resident-centered advocacy.

You can sign-up for updates by emailing info@ltccc.org or calling 212-385-0355. We would love to include you and support your efforts to improve care!

Forms & Resources For Resident-Centered Advocacy

The following forms and tools are free to use [...]
Forms & Resources For Resident-Centered Advocacy

The following forms and tools are free to use and share. They are available in both Word and PDF formats. Please choose the format which works best for you.

**Word files:**
- Resident Concern Record Keeping Form
- Resident Assessment Worksheet
- Resident Preferences Form

**PDF files:**
- Resident Concern Record Keeping Form
- Resident Assessment Worksheet
- Resident Preferences Form

Share This Story, Choose Your Platform!
My Personal Preferences

Like everyone else, residents have preferences in respect to how they live their lives. Federal law requires that every residents’ preferences are recognized, respected, and reflected in the care and services they receive. While living with other people inevitably results in some compromises, the facility must take meaningful steps to meet each resident’s needs and preferences as an individual.

For example, Sam likes to eat meat. This does not mean that the facility must feed Sam filet mignon. However, it is required to provide tasty, appealing, and nutritious food at every meal, and should endeavor to regularly offer dishes that Sam enjoys. Offering Sam a cheese sandwich as a meal substitute on a regular basis is not appropriate.

Residents and families are encouraged to use this form to document preferences which can be shared with staff to foster person-centered care. This page provides basic information. The following pages provide more specifics.

**PLEASE NOTE THAT THIS FORM IS TO PROVIDE INFORMATION ON PERSONAL PREFERENCES ONLY. IT IS NOT TO BE USED TO IDENTIFY A RESIDENT’S CLINICAL OR MEDICAL NEEDS, NOR DOES IT SUPPLANT PLANS OF CARE OR MEDICAL RECORDS.**

<table>
<thead>
<tr>
<th>A Little Bit About Me</th>
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<tbody>
<tr>
<td>I prefer to be called:</td>
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<tr>
<td>I like to wake up: Naturally Around ______ o’clock</td>
</tr>
<tr>
<td>My preferred morning routine: Is important to me Includes: ______________________________________</td>
</tr>
<tr>
<td>My bathing preferences: (check all that apply) Bath Shower Sponge bath (other or special notes)</td>
</tr>
<tr>
<td>My music/tv preferences: TV __________________________________________ Music ______________________________________ I generally prefer quiet time in my room</td>
</tr>
<tr>
<td>Some things that I enjoy or find comforting:</td>
</tr>
</tbody>
</table>

For additional information and resources, please visit [www.nursinghome411.org](http://www.nursinghome411.org).

**Additional topics covered:**
- Personal background
- Sleeping
- Dressing
- Grooming
- Activities
- TV & Music
- Social interactions
- Religious/spiritual

Form is available in both PDF & Word formats. Add as little or as much information as you like.
Resident Concern or Complaint Form

Record-Keeping Form For Resident Concerns

This form can be used to keep personal records of a problem or concern and how it is addressed by the facility. Keeping track of who you spoke to and when, what the response was, and what actions were taken to resolve the problem can strengthen your advocacy, both in the facility and beyond. This form can be used to facilitate conversations and follow-up with staff and administration, raise issues at resident or family council meetings, or support a complaint to a government agency.

Date When Issue Occurred or Was Discovered: __________

Issue:

Staff Person(s) Spoken To:

Response/Plan of Action from Staff:

Actions Taken:

For additional information and resources, please visit www.nursinghome411.org.
# Resident Assessment Planning Form

Nursing homes are required to conduct initially and periodically a comprehensive and accurate assessment of each resident’s functional capacity. Federal law requires that it identify and respond to “a resident’s needs, strengths, goals, life history and preferences.” It is very important because it forms the basis for a resident’s care plan, which outlines to services the facility promises to provide.

Federal standards also state “that 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.” The purpose of this form is to assist residents, families, and those working with them to prepare for and participate effectively in the assessment process. It can be used to identify areas of concern related to the required components of the assessment.

**Identification & Demographic Background:**

**Customary Routine:**

**Cognitive Patterns or Issues (e.g., memory loss, dementia, Alzheimer’s, etc.):**

**Communication Challenges or Problems:**

**Vision Problems (e.g., blurry vision, floaters, flashes, etc.):**

**Mood or Behavioral Concerns (e.g., depression, anxiety, anger, etc.):**

**Concerns with Psychosocial Well-being (e.g., appropriate activities, social environment, etc.):**

**Physical Functioning and Structural Problems (e.g., trouble walking, backaches, arthritis, etc.):**

**Continence Issues (e.g., bladder or bowel function, constipation, relying on assistance to go to the bathroom, etc.):**

**Disease diagnoses and health conditions:**

**Dental Problems or Concerns (e.g., toothaches, dental hygiene concerns, dentures, etc.):**

**Nutritional Concerns (e.g., weight loss, lack of interest in eating, difficulty eating, etc.):**

**Skin Conditions (e.g., pressure ulcer concerns, itching, bruises, abnormal lumps, sore areas, etc.):**

**Activities (e.g., are activities engaging for resident, tailored to mental and physical abilities, etc.):**

**Medication Issues or Concerns (e.g., receiving antipsychotic drugs off-label, not receiving medications to relieve pain or anxiety, etc.):**

**Special Treatments and Procedure Concerns (e.g., staff members are not mindful of resident’s food allergies, facility does not provide vegetarian options for meals, etc.):**

If you have any further issues or concerns not described earlier, please write them below:

For additional information and resources, please visit [www.nursinghome411.org](http://www.nursinghome411.org)
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) and F-tag (category of deficiency).]

I. RESIDENT ASSESSMENT [42 CFR 483.20 F-636]

- 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.
  ✓ 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.

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.
Making Your Voice Heard...
Beyond the Nursing Home
Tell Your Story

Tell Your Story About Nursing Home or Assisted Living Care

A few background questions.

Thank you for taking the time to tell your story. Hearing from you helps us to provide a strong voice for better care and life with dignity for residents. Please note that we will never divulge any resident's name, or the name or location of a facility, unless you give us specific permission to do so.

* 1. Are you a:
   - Resident
   - Staff Person
   - Family Member
   - Ombudsman
   - Other (please specify)

* 2. Type of facility.
   - Nursing Home
   - Assisted Living/Adult Home
   - Other (please specify)

* 3. Is the experience you are writing about positive or negative?
   - Positive
   - Negative

* 4. Did the situation involve abuse, neglect, or other problem? Please select all that apply:
   - Neglect
   - Emotional Abuse
   - Physical Abuse
   - Unwanted Discharge From the Facility
   - Food or Dining Issue
   - Sexual Abuse
   - Communication Problem
   - Theft or Loss
   - Other (please specify)

5. Did the situation raise concerns about the care the resident was receiving?
   - Yes
   - No

6. Did the situation raise concerns about the safety of the resident?
   - Yes
   - No

Visit [www.nursinghome411.org](http://www.nursinghome411.org) to fill out or download copies of the form.
Tell Your Story About Nursing Home or Assisted Living Care

A few additional questions.

If your story relates to a problem or concern, your answers to the following questions will help us categorize the types of problems residents are experiencing.

8. Did the situation involve care for a resident with dementia?
   - Yes
   - No

9. Was the resident in the facility for...
   - short-term rehab
   - long term care
   - don't know or unsure

10. Do you feel that this situation caused resident harm?
    - Yes
    - No
    - Don't know/unsure

11. How many residents do you feel were impacted by this situation?
    - None
    - One resident affected
    - Many or all residents affected
    - Don't know/unsure
    - Some residents affected

12. Please tell us your perception of the severity of the problem or situation.
    - No harm (emotional or physical) to resident(s)
    - Risk of harm to resident(s)
    - Resident(s) were seriously harmed (emotionally or physically)
    - Situation or incident resulted in death of resident(s)
    - Resident(s) were harmed (emotionally or physically)

13. Please indicate which of the following most closely reflects the facility's response.
    - They did not respond at all
    - They responded and resolved the incident in a timely manner
    - They responded, but the incident was resolved, but it took too long
    - They said someone would take care of it, but no one did
    - I don't know/unsure

Thank you for telling your story!
For more resources and information on residential care and quality of life, please visit our website, www.nursinghome411.org. To receive notification about future free programs and alerts, please email INFO@LTC.CC.ORG.
Tell Your Story About Nursing Home or Assisted Living Care

Thank you for taking the time to tell your story! You can fill out the form below, or download a copy of the Tell Your Story form by clicking on the button to the right. Please share this with others in your home and community by sharing the link to this page or copies of the form.

Tell Your Story About Nursing Home or Assisted Living Care

A few background questions.

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   - Ombudsman
   - Other (please specify)

* 2. Type of facility:
   - Nursing Home
   - Assisted Living/Adult Home
   - Other (please specify)

* 3. Is the experience you are writing about positive or negative?

[Form fields and buttons for submission and sharing]
“Nothing will happen unless legislators hear from their constituents that this is important.”
STAND UP FOR SAFE STAFFING

Staffing is critical to quality care and dignity for nursing home residents. Yet numerous studies have shown that the majority of nursing homes fail to have sufficient staff to meet a typical resident’s needs. We wouldn’t allow a nursing home to admit 100 residents if it only had 60 beds. Why do we allow nursing homes to admit as many residents as they want, with no minimum staffing requirements, even when the facility has a history of substandard care?

Please send a quick message now to let your political leaders know that the time has come for safe staffing standards in nursing homes.

Not Richard Mellott? Click here to logout.

Contact Information

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<thead>
<tr>
<th>Prefix (Optional)</th>
<th>First Name</th>
<th>Last Name</th>
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<tbody>
<tr>
<td>Mr.</td>
<td>Richard</td>
<td>Mellott</td>
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<tr>
<th>Street Address</th>
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<tbody>
<tr>
<td>1 Pennsylvania Plaza, Suite 6262</td>
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<tr>
<th>Postal Code</th>
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<td>10119</td>
<td>New York</td>
<td>NY</td>
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<tr>
<th>Email</th>
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<tr>
<td><a href="mailto:richard@ltccc.org">richard@ltccc.org</a></td>
<td>212-385-0355</td>
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Update my FastAction profile with this information.

Personalize your subject

I am writing to you today regarding a very important issue, Safe Staffing for Nursing Home Residents.

Dear [elected official],

Personalize your message

I am writing to you in regard to nursing home staffing, one of the most important factors in the quality of care that nursing home residents receive and the quality of life that they enjoy. Sadly, I have learned that nursing homes all too often fail to provide the adequate staffing that is necessary to meet the needs of their residents. As a result, vulnerable residents suffer.

Recently, The New York Times found that nursing homes actually have less staffing than they were previously reporting to the Centers for Medicare & Medicaid Services (CMS). A new reporting system based on payroll-based data, rather than the previously used self-reported data, has shown that seven out of ten nursing homes have lower staffing than previously reported to the public. The new, verifiable data indicate that some nursing homes are even failing to provide any registered nurse care at times. I hope you will agree that this is a significant betrayal of the public trust.

Every nursing home is paid, and required by law, to have sufficient staff with the competencies and skills needed to meet the care needs of each resident. However, these minimum standards are often undermined by poor enforcement or manipulation, as The New York Times article suggests. Given this reality, nursing home residents need the protection of more robust staffing and enforcement requirements.

Years of research and the experiences of millions of nursing home residents and their families point to the need for safe staffing.

Sincerely,

[Your information here]
Recap

Know your rights:

- Have a concern or question? Visit the Learning Center @ www.nursinghome411.org to find the Fact Sheet or Issue Alert that relates to your concern.
- Download a copy of the LTCCC Primer: Essential Nursing Home Quality Standards which provides searchable information on a range of standards that are relevant to resident care, dignity, and quality of life. It can be a useful resource for resident and family councils, LTC ombudsmen, and other advocates.

Use your knowledge & the resources:

- The Learning Center has easy-to-use forms and tools to support your advocacy.
- In the facility:
  - Speak to staff and administration: how can they help you achieve the rights to which you are entitled?
  - Seek help from the LTC ombudsman or call the LTC Ombudsman Program.
  - Work with other residents and families.
  - Register your concerns with the Grievance Officer.
- Outside of the facility: If the problem cannot be addressed with facility staff, your knowledge of the rules and the LTCCC resources can support a complaint to the state Department of Health, Medicaid Fraud Control Unit, Law Enforcement, or an elder abuse attorney.
Next Program: December 18 at 1pm.

Topic: Staffing: How to Find Out About Staffing in Your Facility & What it Means for Your Resident’s Care & Quality of Life
Thank You For Joining Us Today!

Email info@ltccc.org or call 212-385-0355 for...

- Invites to future programs,
- News and alerts on important care issues.

- Join us on Facebook at www.facebook.com/ltccc
- Follow us on Twitter at www.twitter.com/LTCconsumer

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: 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).
Questions?  

Comments?

Presentation materials and the webinar recording will be posted on www.nursinghome411.org after each program for future reference.