

# 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.
- Richard Mollot: Joined LTCCC in 2002. Executive director since 2005.

## + 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.



### + Persistent Problems

# 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.

+ Persistent Problems – Why?

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.

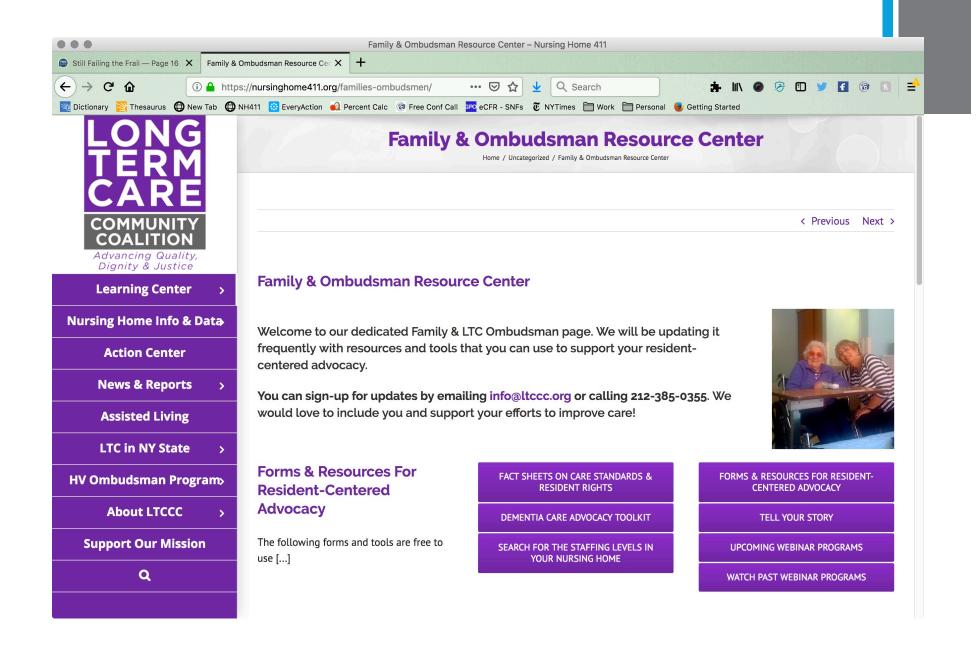
# + Who to Speak to....

- 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.

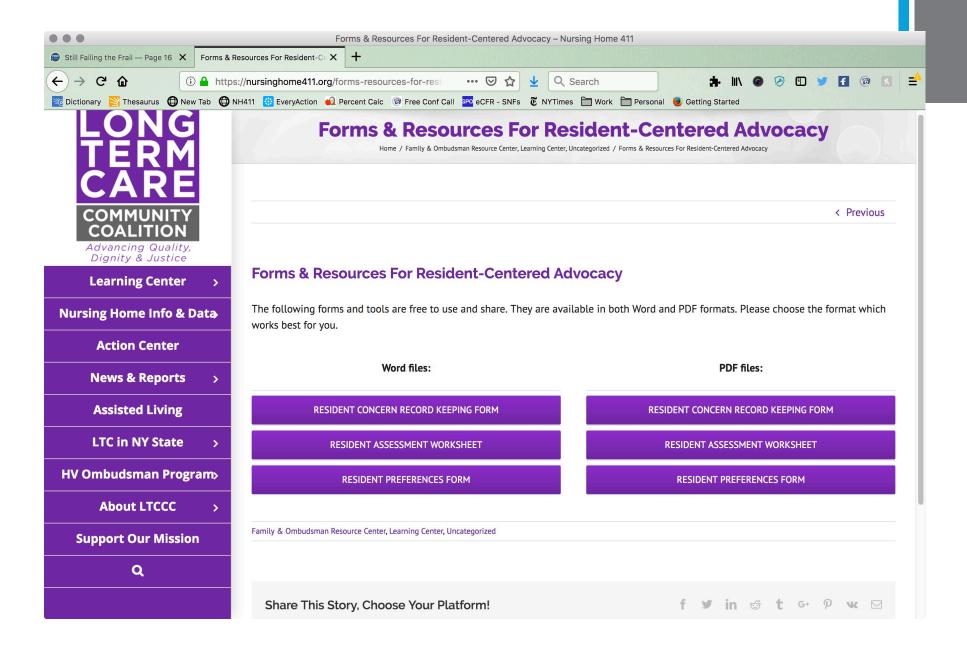
# Important Note:

These are some general suggestions. It is important, however, to always act in the best interest of the safety of residents, staff, and visitors.

### + Tools: Family & Ombudsman Resource Center



# + Tools: Forms & Resources Page



### + Resident Preferences Form

Name:	
	-

#### **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.

	A Little Bit About Me
I prefer to be called:	
I like to wake up:	Naturally Aroundoʻclock
My preferred morning routine:	Is important to me Includes:
My bathing preferences: (check all that apply)	Bath Shower Sponge bath
	(other or special notes)
My music/tv preferences:	TV
	Music I generally prefer quiet time in my room
Some things that I enjoy or find comforting:	

For additional information and resources, please visit 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

	Today's Date:
Record-Keeping Form For Residen	nt Concerns
This form can be used to keep personal records of a problem or co facility. Keeping track of who you spoke to and when, what the respo to resolve the problem can strengthen your advocacy, both in the used to facilitate conversations and follow-up with staff and admin family council meetings, or support a complaint to a government age	onse was, and what actions were take facility and beyond. This form can b nistration, raise issues at resident of
Date When Issue Occurred or Was Discovered:	
Issue:	
Staff Person(s) Spoken To:	
Response/Plan of Action from Staff:	
Actions Taken:	

Today's Date:
Today's Date:

### + Resident Assessment Planning Form

Resident Assessment Planning Form
Nursing homes are required to conduct initially and periodically a comprehensive and accura assessment of each resident's functional capacity. Federal law requires that it identify and respond "a resident's needs, strengths, goals, life history and preferences." It is very important because it for 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 a communication with the resident, as well as communication with licensed and nonlicensed direct cast aff members on all shifts." The purpose of this form is to assist residents, families, and those worki with them to prepare for and participate effectively in the assessment process. It can be used to ident areas of concern related to the required components of the assessment.
dentification & 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):
For additional information and resources, please visit

www.nursinghome411.org.

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:

Continence Issues (e.g., bladder or bowel function, constipation, relying on assistance to go to the

For additional information and resources, please visit www.nursinghome411.org.

### + Fact Sheet: Resident Assessment & Care Planning

### 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.

Use this checklist to

identify what is

important to YOU

when you have a

resident assessment!

- 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.

#### 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.
- o 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

<u>WWW.NURSINGHOME411.ORG</u>. LTCCC's website includes materials on the relevant standards for nursing home care, training materials and other resources.

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# Making Your Voice Heard... Beyond the Nursing Home

### + Tell Your Story

few background question	S.	
oice for better care and life	e to tell your story. Hearing from you with dignity for residents. Please no e or location of a facility, unless you	te that we will <u>never</u> divulge any
1. Are you a:		
Resident	Staff Pers	son
Family Member	Ombudsn	nan
Other (please specify)		
2. Type of facility.		
Nursing Home	( ) Assisted	Living/Adult Home
Other (please specify)		
3. Is the experience you are	e writing about positive or negative?	
Positive	Negative	
4. Did the situation involve	abuse, neglect, or other problem? Pleas	se select all that apply:
Neglect	Unwanted Discharge From the F	Facility Medication
Emotional Abuse	Food or Dining Issue	Communication Problem
Physical Abuse	Sexual Abuse	Theft or Loss
Other (please specify)		_
	ncerns about the care the resident was	receiving?
Yes	○ No	
6 Did the cituation raise co	ncerns about the safety of the resident?	?
o. Did the situation raise to		

	About Nursing Home or Assisted Living Care
Please tell you	ır story here.
	e as much space as you like to provide details of your story. We appreciate hearing about any matters to you, whether it is about a good experience or bad experience.

Visit <a href="https://www.nursinghome411.org">www.nursinghome411.org</a> to fill out or download copies of the form.

### + Tell Your Story

vision atomi valetos to a visibless		to the following greeting will help ve
tegorize the types of problems		to the following questions will help us j.
8. Did the situation involve care	or a resident with dementia?	
Yes	O No	
9. Was the resident in the facility	for	
short-term rehab	Ong term care	on't know or unsure
10. Do you feel that this situation	caused resident harm?	
Yes	○ No	Oon't know/unsure
11. How many residents do you	, ,	
None Spanisher to Manager	0	ny or all residents affected
One resident affected  Some residents affected	<u> </u>	n't know/unsure
Some residents affected		
12. Please tell us your perception	n of the severity of the proble	em or situation.
No harm (emotional or physical) to	resident(s) Re	sident(s) were seriously harmed (emotionally or physicall
Risk of harm to resident(s)	Sit	uation or incident resulted in death of resident(s)
Resident(s) were harmed (emotion	ally or physically)	
13. Please indicate which of the	following most classic reflect	te the facility's recogne
They did not respond at all		ey said someone would take care of it, but no one did
They responded and resolved the		id not tell the facility
They responded and the incident v	. 0	on't know
You are welcome to provide details here		

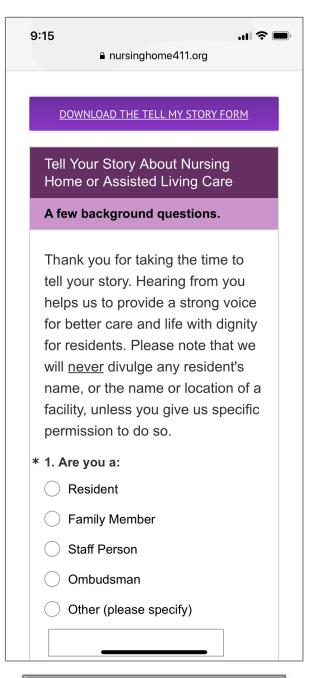
Please tell us a little	e about you (optional).
	ring information you provide us in this survey, including any answers you be kept strictly confidential unless you give us specific permission otherwise.
14. Address	
Name	
Address	
City/Town	
State/Province	
ZIP/Postal Code	
Email Address	
Yes (Please prov	ct you in the future to share more about your story? ide contact information below)  ame, email, and/or phone number.
	ur story! Information on residential care and quality of life, please visit our website, <a href="www.nursinghome411.org">www.nursinghome411.org</a> . To uture free programs and alerts, please email INFO@LTCCC.ORG.

Visit <a href="https://www.nursinghome411.org">www.nursinghome411.org</a> to fill out or download copies of the form.

### + Tell Your Story

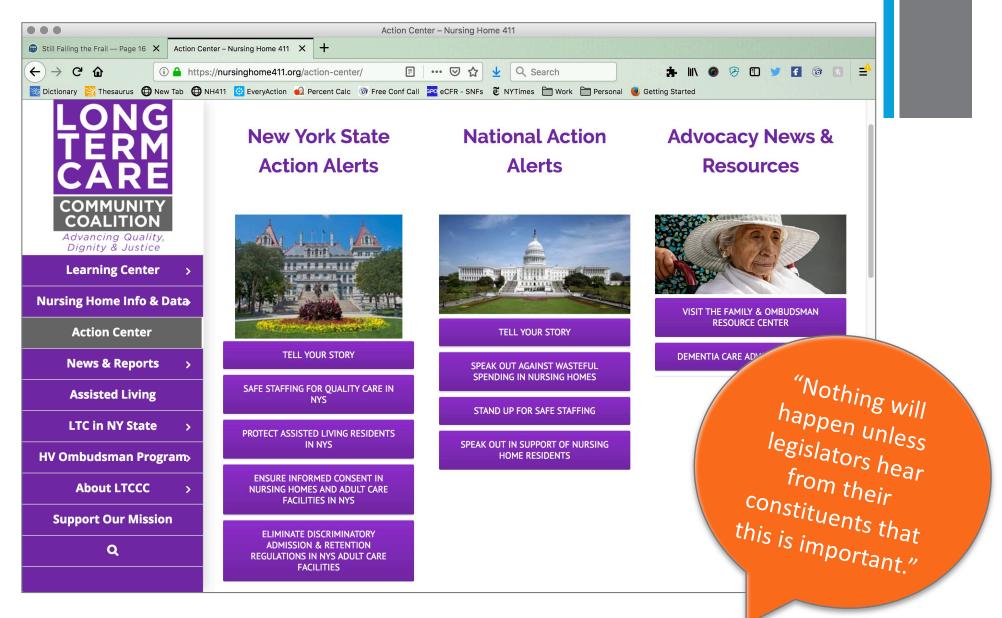
LONG TERM CARE	Tell Your Story About Nursing Home or Assisted Living  Care
COMMUNITY COALITION Advancing Quality, Dignity & Justice	< Previous Next >
Learning Center >	Tell Your Story About Nursing Home or Assisted Living Care
Nursing Home Info & Data	Thank you for taking the time to tell your story! 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.  MY STORY FORM
Action Center	Please share this with others in your home and community by sharing the link to this page or copies of the form.
News & Reports >	
Assisted Living	Tell Your Story About Nursing Home or Assisted Living Care
LTC in NY State >	A few background questions.
HV Ombudsman Program>	Thank you for taking the time to tell your story. Hearing from you helps us to
About LTCCC >	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
Support Our Mission	a facility, unless you give us specific permission to do so.
Q	* 1. Are you a:
	Resident Staff Person
	Share This Story, Choose Your Platform! f 🔰 in 😅 t 🙃 👂 🕦

Computer Screenshot



### iPhone Screenshot

# + Speak Out to Policymakers



### + Sample Alert



#### 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

ot Richard Mollot? Click here to logout.				fast <b>Action</b>
Contact Information				
refix (Optional)	<u>First Name</u>		<u>L</u> ast Name	
Mr. 🗡	Richard	<i>&gt;</i>	Mollot	7
treet Address				
1 Pennsylvania Plaza, Suite 6252	2			7
ostal Code	City		State/Provin	nce
10119	New York	>	NY	
mail		Home Phone	(Optional)	
richard@ltccc.org	7	212-385-0	355	7
ersonalize your subject I am writing to you today regardi	ing a very important issue, S	afe Staffing for Nurs	sing Home Residents.	
	ing a very important issue, S	afe Staffing for Nurs	sing Home Residents.	
l am writing to you today regardi lear [elected official], ersonalize your message		•		
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l am writing to you today regardi lear [elected official], ersonalize your message I am writing to you in regard to n residents receive and the quality	oursing home staffing, one of of life that they enjoy. Sadly ary to meet the needs of the bound that nursing homes act of Services (CMS). A new repata, has shown that seven ou data indicate that some nur	the most important I, I have learned that ir residents. As a re- ually have less staff orting system based t of ten nursing hom	t factors in the quality inursing homes all too sult, vulnerable resider ing than they were pre on payroll-based dat see shave lower staffing	o often fail to provide the nts suffer.  eviously reporting to the a, rather than the g than previously reported
l am writing to you today regardi lear [elected official], ersonalize your message I am writing to you in regard to n residents receive and the quality adequate staffing that is necess! Recently, The New York Times for Centers for Medicare & Medicaic previously used self-reported da to the public. The new, verifiable	oursing home staffing, one of of life that they enjoy. Sadly ary to meet the needs of the bound that nursing homes act of Services (CMS). A new repata, has shown that seven ou data indicate that some nur this is a significant betrayal required by law, to have suff r, these minimum standards	the most important I, I have learned that ir residents. As a retuilly have less staff orting system based to fit en nursing hom sing homes are even of the public trust.	t factors in the quality t nursing homes all toc sult, vulnerable reside ing than they were pre d on payroll-based dat nes have lower staffing in failing to provide any competencies and ska	often fail to provide the nots suffer.  In suffer.  In our porting to the a, rather than the the than the the than the than the than the than the than the than the the than the the than the the than the

http://www.nursinghome411.org



## + 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:

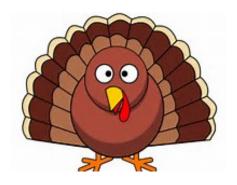
- The Learning Center has easy-to-use forms and tools to support your advocacy.
- o In the facility:
  - Speak to staff and administration: how can they help you achieve the rights to which you are entitled?
  - ✓ Seek help from the LTC ombudsman or call the LTC Ombudsman Program.
  - ✓ Work with other 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 <u>www.facebook.com/ltccc</u>
- Follow us on **Twitter** at <u>www.twitter.com/LTCconsumer</u>
- 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:

www.surveymonkey.com/r/ltccc-ltcop1.

**For Family Members in NY State** 

connect with the Alliance of NY Family Councils at <a href="https://www.anyfc.org">www.anyfc.org</a> (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.