



# Understanding and Advocating for Residents with Dementia in the Time of COVID-19

Richard Mollot & Eric Goldwein

The Long Term Care Community Coalition

[www.nursinghome411.org](http://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). Home to two local LTC Ombudsman Programs in NY.
- **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.
- **Eric Goldwein:** Joined LTCCC in 2019. Policy & Communications Director since 2005.
- **Richard Mollot:** Joined LTCCC in 2002. Executive Director since 2005.
- **Website:** [www.nursinghome411.org](http://www.nursinghome411.org).



## + Today's Program:

- Update on COVID-19 policy developments of interest & concern.
- LTCCC's COVID-19 resource page.
- Dementia care considerations.
- Resources to dementia care advocacy .
- Time for discussion & questions.





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# COVID-19

New Federal Reporting Requirements &  
Plans to “Open” Nursing Homes

# + NEW FEDERAL REQUIREMENTS FOR COVID-19 (May 8, 2020)

## § 483.80 Infection control. (g) COVID-19 Reporting.

The facility must electronically report information about COVID-19 in a standardized format specified by the Secretary. This report must include but is not limited to-

- (i) Suspected and confirmed COVID-19 infections among residents and staff, including residents previously treated for COVID-19;
- (ii) Total deaths and COVID-19 deaths among residents and staff;
- (iii) Personal protective equipment and hand hygiene supplies in the facility;
- (iv) Ventilator capacity and supplies in the facility;
- (v) Resident beds and census;
- (vi) Access to COVID-19 testing while the resident is in the facility;
- (vii) Staffing shortages; and
- (viii) Other information specified by the Secretary.

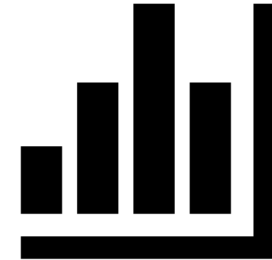
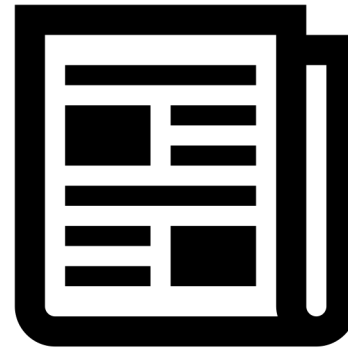


WHAT

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## + Federal Reporting Requirements (May 8, 2020):

- Information must be provided weekly to the Centers for Disease Control & Prevention (CDC). [CMS can require more frequent reporting.]
- “This information will be posted publicly by CMS to support protecting the health and safety of residents, personnel, and the general public.”



WHEN &  
WHERE

**CMS anticipates publicly posting CDC's NHSN data (including facility names, number of COVID-19 suspected and confirmed cases, deaths, and other data as determined appropriate) weekly on <https://data.cms.gov/> by the end of May.**

## + Federal Reporting Requirements (May 8, 2020):

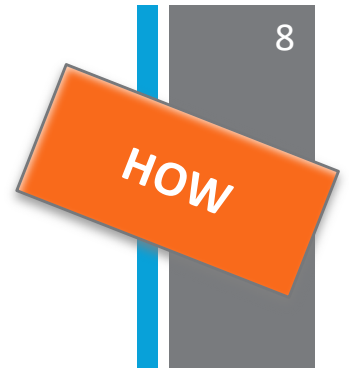
Nursing homes must inform residents, their representatives, and families of those residing in facilities by 5 p.m. the next calendar day following the occurrence of either

1. A single confirmed infection of COVID-19, or
2. Three or more residents or staff with new-onset of respiratory symptoms occurring within 72 hours of each other.

There are a variety of ways that facilities can meet this requirement, such as informing families and representatives through email listservs, website postings, paper notification, and/or recorded telephone messages. We do not expect facilities to make individual telephone calls to each resident's family or responsible party to inform them that a resident in the facility has laboratory-confirmed COVID-19.



## + Federal Reporting Requirements (May 8, 2020):



This information must—

1. **Not include** personally identifiable information;
2. **Include** information on mitigating actions implemented to prevent or reduce the risk of transmission, including if normal operations of the facility will be altered; and
3. **Include** any cumulative updates for residents, their representatives, and families...



- At least weekly or
- by 5 p.m. the next calendar day following the subsequent occurrence of either:
  - a. each time a confirmed infection of COVID-19 is identified, or
  - b. whenever three or more residents or staff with new onset of respiratory symptoms occur within 72 hours of each other.



## + Federal “Recommendations” for Opening Nursing Homes

CMS recommends that “decisions on relaxing restrictions should be made with careful review of a number of facility-level, community, and State factors/orders, and in collaboration with State and/or local health officials and nursing homes.”

Factors to consider include:

- **Case status in community:** Decline in the number of new cases, hospitalizations, or deaths.
- **Case status in the nursing home(s):** Absence of any new nursing home onset<sup>1</sup> of COVID-19 cases (resident or staff), such as a resident acquiring COVID-19 in the nursing home.
- **Adequate staffing:** No staffing shortages and the facility is not under a contingency staffing plan.

## + Federal “Recommendations” for Opening Nursing Homes (continued)

- **Access to adequate testing.**
- **Residents and visitors wear a cloth face covering or facemask:** If a visitor is unable or unwilling to maintain these precautions (such as young children), consider restricting their ability to enter the facility. All visitors should maintain social distancing and perform hand washing or sanitizing upon entry to the facility.
- **Access to adequate Personal Protective Equipment (PPE) for staff:** All staff wear all appropriate PPE when indicated. Staff wear cloth face covering if facemask is not indicated, such as administrative staff.
- **Local hospital capacity:** Ability for the local hospital to accept transfers from nursing homes.

# + Coronavirus Resource Center

[NURSINGHOME411.ORG/CORONAVIRUS/](https://nursinghome411.org/coronavirus/)

**COVID-19 Resources**   **News & Reports**   **Data**   **Federal Guidance**

LTCCC'S EMERGENCY ACTION PLAN FOR NY STATE

LTCCC'S NEW YORK TIMES OP-ED: NURSING HOMES WERE A DISASTER WAITING TO HAPPEN

ISSUE ALERT: INFECTION CONTROL & PREVENTION

MARCH 2020: NEW GUIDANCE ON NURSING HOME HEALTH INSPECTIONS SEVERELY LIMITS OVERSIGHT AND ENFORCEMENT

MARCH 2020 STATEMENT: CORONAVIRUS & NURSING HOME VISITATION

Opinion

## Nursing Homes Were a Disaster Waiting to Happen

Long before Covid-19, poor care and lax standards were widespread and well known.

**By Richard Mollot**  
Mr. Mollot is the executive director of the Long Term Care Community Coalition.

April 28, 2020

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# + Coronavirus Resource Center

## RESOURCES

- Fact Sheets
  - Infection Control
  - Stimulus Checks (Center for Elder Law & Justice)
- LTCCC's Nursing Home 411 Podcasts
- Webinars
  - Promising Practices and Recommendations for Evaluating Nursing Home Owners
  - National Consumer Voice: Advocating for Nursing Home Residents

# + Coronavirus Resource Center

## NEWS & REPORTS

- LTCCC'S Emergency Action Plan for NY State
- Infection Control Issue Alert
- LTCCC's New York Times Op-Ed

### LONG TERM CARE COMMUNITY COALITION

*Advancing Quality, Dignity & Justice*

#### EMERGENCY ACTION PLAN:

##### Save Lives of Residents in New York Long Term Care Facilities

##### **Stop COVID-19 from being introduced to skilled nursing facilities**

Order facilities with no known or suspected COVID-19 outbreaks to refuse admission to any outside patients with known or suspected COVID-19. When COVID-19 enters nursing homes, it is highly likely to spread to the resident population which is particularly vulnerable to the virus.

Establish COVID-19 dedicated post-acute care facilities across the state and require all hospital post-discharge patients to be tested for COVID-19 and, if positive, transferred to such facilities. Transfers of current skilled nursing facility residents during the pandemic should be kept to a minimum and closely monitored by the Department of Health.

##### **Monitor facilities with residents who have COVID-19 on a daily basis**

Assign a NYS Department of Health (DOH) surveyor to conduct daily onsite monitoring visits at each facility with residents who have COVID-19 to ensure infection control practices and staffing levels are safe and to sound the alarm on the need for immediate intervention if they are not.

# + Coronavirus Resource Center

## DATA

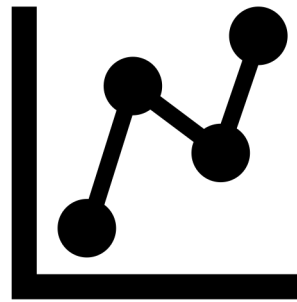
### ■ COVID-19 Fatalities

- New York
- National

### ■ Staffing

### ■ Provider Info

### ■ Infection Control & Citations

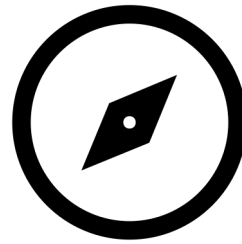


NY COVID-19 FATALITY DATA (05/11/20)	
Confirmed at NH	2,706
Presumed at NH	2,646
Confirmed + Presumed at NH	5,352
Confirmed at ACF	112
Presumed at ACF	52
Confirmed + Presumed at ACF	164
<b>Total</b>	<b>5,516</b>

Source: NY DOH

# + Coronavirus Resource Center

## FEDERAL GUIDANCE



- CMS Toolkit
  - State actions for COVID-19 management
  - Telehealth
  - Organizations assisting nursing homes
- CDC Fact Sheets and resources





# LONG TERM CARE COMMUNITY COALITION

*Advancing Quality, Dignity & Justice*

Visit our home page

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

for

- Coronavirus resources & updates;
- Fact sheets on nursing home resident rights;
- Data on staffing, infection control violations, and ratings for all U.S. nursing homes;
- Forms & tools for resident-centered advocacy;
- Dementia Care Advocacy Toolkit;
- And more!

Sign up for alerts @

<https://nursinghome411.org/join/>.

Listen to our *new* Nursing Home 411 podcast on Spotify & Apple Podcasts.

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

[www.twitter.com/LTCconsumer](https://www.twitter.com/LTCconsumer)

[www.facebook.com/ltccc](https://www.facebook.com/ltccc)

[feedback@ltccc.org](mailto:feedback@ltccc.org)





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# Dementia Care

Advocacy & Other Considerations in the Age  
of COVID-19

# + Basic Concerns

- Is my resident getting necessary care?
  - ▶ COVID-19
  - ▶ Help with eating and drinking
  - ▶ Bathing
  - ▶ Toileting
  - ▶ Maintenance of health services
  - ▶ Appropriate medication: YES to beneficial meds/NO to antipsychotics and other psychotropics (unless prescribed to treat a diagnosed condition)
  
- Is my resident unhappy or uncomfortable?
  - ▶ Able to communicate with family, others
  - ▶ Appropriate activities
  - ▶ Treated with dignity and kindness

## + Federal Standards

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.

While a few of the federal nursing home requirements have been relaxed during the COVID-19 emergency (such as some transfer and discharge rules), the basic care, safety, and dignity standards are still in effect.

## + Federal Standards

- **Necessary Care & Services:** Every resident, including those with dementia, has the right to receive the care and services necessary to attain and maintain highest possible well-being and functioning.
- **Dignity:** Every resident, including those with dementia, has the right to be treated with dignity and respect and to live in a comfortable environment.
- **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. If a resident lacks capacity, his or her loved one can exercise these rights on the resident's behalf.
- **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.

## + Federal Standards

Nursing homes are required under federal law to have sufficient staffing, PPE, or other resources to safely and appropriately care for every resident that they accept or retain.

If facilities are experiencing staffing or other shortages, they have a legal obligation to not accept additional residents and to arrange for the safety and appropriate care of the residents they have (either by bringing in more staff/supplies or arranging for a safe and appropriate transfer to another setting).



# + Alternate Ideas for Activities & Engagement

Note: The ability to access and/or partake in activities will vary based upon both the individual and his/her abilities and preferences as well as the situation in the facility. The following ideas may or may not work for your resident. We encourage considering what the resident liked doing throughout his/her life and adapting those activities, to the extent possible, to the current situation.

- Provide music via iPod or smartphone.
- Keep in touch over phone or FaceTime/Zoom.
- Escorted walk outside or in a sunny place in facility.
- Visit through a window in a courtyard or reception area.
- Send drawings from grandchildren or copies of photos, pictures that the individual would enjoy.
- Ask for or provide food that resident enjoys, such as cookies, chocolate, or a glass of wine.
- Put together a rummage box of things the individual has been interested in.
- Provide puzzles, games, or reading material appropriate to the individual's interests and abilities.





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Resources to Support Resident-  
Centered Advocacy.

# + The Dementia Care Toolkit

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



These tips  
are useful for  
any setting!

## LONG TERM CARE COMMUNITY COALITION

*Advancing Quality, Dignity & Justice*

### CONSUMER FACTSHEET: DEMENTIA CARE CONSIDERATIONS

Assessing 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](http://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](http://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](http://WWW.THECONSUMERVOICE.ORG). The Consumer Voice has numerous materials and resources for residents, family members and LTC Ombudsmen.



# + 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.<sup>1</sup>*

#### 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](http://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](http://WWW.THECONSUMERVOICE.ORG). The Consumer Voice has numerous materials and resources for residents, family members and LTC Ombudsmen.

<sup>1</sup> 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

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

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### 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](http://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 Care 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



**Thank you to the Fan Fox & Leslie R. Samuels Foundation for supporting the development of this toolkit, and to the family councils who welcomed us to their meetings!**

# + Family & Ombudsman Resource Center

Family & Ombudsman Resource Center – Nursing Home 411

Family & Ombudsman Resource Center X

https://nursinghome411.org/families-ombudsmen/

Dictionary Thesaurus NH411 EveryAction Percent Calc Email & Office Free Conf Call eCFR - SNFs NYTimes Work Personal Violation Tracker | ... Getting Started

## LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

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### Family & Ombudsman Resource Center


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#### 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](mailto:info@ltccc.org) or calling 212-385-0355. We would love to include you and support your efforts to improve care!



#### Resident Rights Handouts

LTCCC's handouts provide basic, easy-to-understand information on issues that [...]

- FACT SHEETS ON CARE STANDARDS & RESIDENT RIGHTS
- DEMENTIA CARE ADVOCACY TOOLKIT
- SEARCH FOR THE STAFFING LEVELS IN YOUR NURSING HOME
- HANDOUTS ON KEY NURSING HOME ISSUES

- FORMS & TOOLS FOR RESIDENT-CENTERED ADVOCACY
- TELL YOUR STORY
- UPCOMING WEBINAR PROGRAMS
- WATCH PAST WEBINAR PROGRAMS

#### Upcoming Webinars: Nursing Home Care & Resident-

# + Forms & Tools for Resident-Centered Advocacy

The screenshot shows a web browser window with the following elements:

- Browser Tab:** Forms & Tools For Resident-Centered Advocacy - Nursing Home 411
- Address Bar:** <https://nursinghome411.org/forms-tools-resident-centered->
- Navigation Bar:** Includes links for Dictionary, Thesaurus, NH411, EveryAction, Percent Calc, Free Conf Call, eCFR - SNFs, NYTimes, Work, Personal, Violation Tracker, and Getting Started. A user profile for 'Howdy, Richard' is visible on the right.
- Logo:** TERM CARE COMMUNITY COALITION. Advancing Quality, Dignity & Justice.
- Sidebar (Left):** A vertical menu with the following items: Learning Center, Nursing Home Info & Data, Action Center, News & Reports, Assisted Living, LTC in NY State, HV Ombudsman Program, About LTCCC, and Support Our Mission. A search icon is at the bottom.
- Main Content Area:**
  - Title:** Forms & Tools For Resident-Centered Advocacy
  - Text:** 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:** A column of seven purple buttons: RESIDENT CONCERN RECORD KEEPING FORM, RESIDENT ASSESSMENT WORKSHEET, RESIDENT PREFERENCES FORM, FAMILY COUNCIL MEETING NOTICE, RESIDENT COUNCIL MEETING NOTICE, RESIDENT COUNCIL MEETING AGENDA, and FAMILY COUNCIL MEETING AGENDA.
  - PDF files:** A column of seven purple buttons: RESIDENT CONCERN RECORD KEEPING FORM, RESIDENT ASSESSMENT WORKSHEET, RESIDENT PREFERENCES FORM, FAMILY COUNCIL MEETING NOTICE, RESIDENT COUNCIL MEETING NOTICE, RESIDENT COUNCIL MEETING AGENDA, and FAMILY COUNCIL MEETING AGENDA.
  - Footer:** Family & Ombudsman Resource Center, Learning Center

# + Resident Preferences Form

Name: \_\_\_\_\_

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## 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:	<input type="checkbox"/> Naturally <input type="checkbox"/> Around _____ o'clock
My preferred morning routine:	<input type="checkbox"/> Is important to me <input type="checkbox"/> Includes: _____
My bathing preferences: (check all that apply)	<input type="checkbox"/> Bath <input type="checkbox"/> Shower <input type="checkbox"/> Sponge bath <input type="checkbox"/> _____ (other or special notes)
My music/tv preferences:	<input type="checkbox"/> TV _____ <input type="checkbox"/> Music _____ <input type="checkbox"/> 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](http://www.nursinghome411.org).

Name: \_\_\_\_\_

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## Get to Know Me

I have lived in this facility since:	_____
My religious and cultural traditions are:	_____
An interesting fact about me is:	_____
People in whom I am interested:	<input type="checkbox"/> Spouse or partner _____ <input type="checkbox"/> Friends _____ <input type="checkbox"/> Children _____ <input type="checkbox"/> Grandchildren _____ <input type="checkbox"/> Other _____
My birthday is: (Write N/A if you prefer not to say)	_____
Some things I like:	_____
Some things I don't like:	_____
When I feel unwell or upset, I like people to:	_____
Favorite activities:	<input type="checkbox"/> Now _____ <input type="checkbox"/> In the past _____
Favorite food:	_____
Animals I like:	<input type="checkbox"/> Dogs <input type="checkbox"/> Cats <input type="checkbox"/> Other: _____ <input type="checkbox"/> I don't care for animals

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

# + Record-Keeping Form for Resident Concerns

Today's Date: \_\_\_\_\_

**Record-Keeping Form For Resident Concerns**

This form can be used to keep 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:

People Involved or Witnesses (if any):

Staff Person(s) Spoken To:

Response/Plan of Action from Staff:

Actions Taken:

This form can be used by individual residents and families, as well as resident and family councils, to track concerns for discussion with facility staff, state surveyors, legislators, etc....

# + Family Council Meeting Agenda

## LONG TERM CARE COMMUNITY COALITION

WWW.NURSINGHOME411.ORG

### FAMILY COUNCIL MEETING AGENDA

[This agenda serves as a template. Add or subtract items to customize it for your meetings.]

Meeting Date: \_\_\_\_\_

1. President: Call to Order and Roll Call
2. Welcome and Introduction of New Members
3. Invited Speaker (if any)
4. Secretary: Read Minutes from Last Meeting; Member Vote to Approve
5. Council Old Business (if any)

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6. Committee Reports and Updates

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- Over Please -

FAMILY COUNCIL MEETING AGENDA – Page 2

7. Discussion of New Business, Including any Care and Quality of Life Concerns

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8. Action Items (if any)

- Issues to Raise Within Facility (Such as with Administrator or Quality Assurance Committee):

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- Issues to Raise Outside of Facility (Such as with Health Department, Medicaid Fraud Control Unit, or legislators):

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9. Confirmation of Next Meeting and Adjournment

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ADDITIONAL  
RESOURCES

Visit [www.nursinghome411.com](http://www.nursinghome411.com) for free resources on residents' rights and tools that you can use to support your resident-centered advocacy.



## + Coming Up

# Identifying and Addressing Nursing Home Abuse & Neglect

**June 16 at 1pm**

### Attend 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).

# + Thank You For Joining Us Today!

Visit [nursinghome411.org/join/](http://nursinghome411.org/join/) 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)).

