

### Focus on Residents' Rights... Visitation, Resident Records, & Communication

Long Term Care Community Coalition 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.

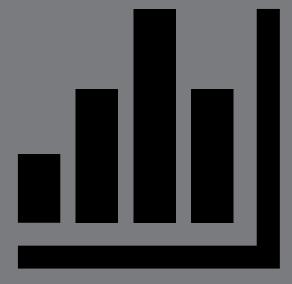
### What we do:

- Policy analysis and systems advocacy in NYS & nationally;
- Education of consumers and families, LTC Ombudsmen and other stakeholders.
- Eric Goldwein: LTCCC's Policy & Communications Director. Joined LTCCC in 2019.
- Richard Mollot: LTCCC's Executive Director. Joined LTCCC in 2002.
- Website: <u>www.nursinghome411.org</u>.



- Update on COVID-19 data and policy developments.
- Residents' Rights...
  - ✓ Visitation;
  - Access to resident records; and
  - ✓ Communication.
- Resources





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## COVID-19 Data Update

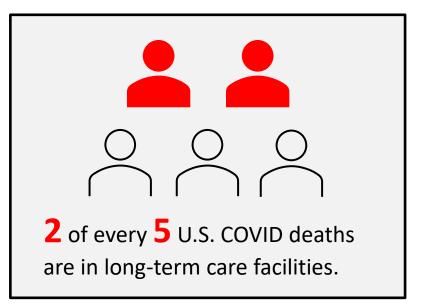
## + COVID-19 Data Update: LTC Cases & Fatalities

### US LTC Totals

- Kaiser Family Foundation
  - 537,000 LTC cases (resident & staff)
  - **84,000** LTC deaths (220,000 overall)
  - 21,000 LTC facilities
  - Varies by state, community, etc.
- CMS (October 15)
  - **397,000** LTC cases
  - **59,626** LTC deaths
  - Only includes nursing homes
  - Source: https://nursinghome411.org/facility -level-covid-data/

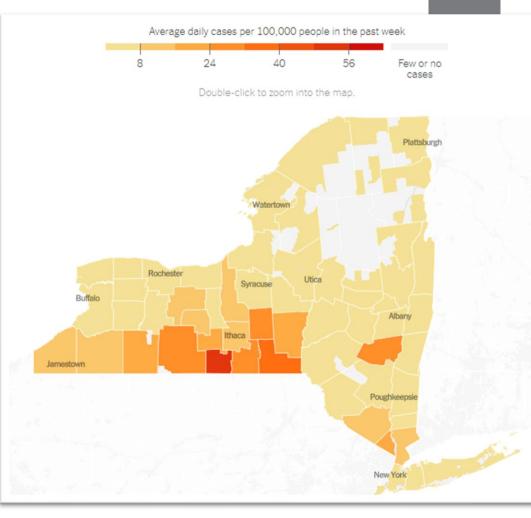
### CAUTION! Take data with a grain of salt.

- Underreporting
- Data entry errors
- Discrepancies
- It's not just cases & fatalities
  - Isolation, abuse, neglect, substandard care, etc.



# + New York's COVID Cases & Fatalities

- NY DOH (October 12)
  - 6,692 LTC deaths in New York state nursing homes & adult care facilities
  - Excludes fatalities occurring outside facility
  - Plateauing deaths, but rising in some counties (Erie, Steuben)
    - Steuben's Corning Center nursing home reports 25 COVID-related deaths
    - Source: <u>https://nursinghome411.org/ny-nursinghome-covid-data/</u>
- Warning signs in New York state. In the past week....
  - Daily reported cases rose 1.6%
  - Daily reported deaths rose 40%
  - COVID-related hospitalizations rose 6.4%
  - Source: Washington Post



#### Source: NY Times

## Residents Rights...

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Voting

# What are the Voting Rights of LTC Residents

- Federal rules for nursing homes protect residents' voting rights
  - §483.10(b) The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.
  - §483.10(b)(1) The facility must ensure that the resident can exercise his or her rights without interference, coercion, discrimination, or reprisal from the facility.
  - §483.10(b)(2) The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights and to be supported by the facility in the exercise of his or her rights as required under this subpart.

 "The right to vote is a fundamental right and living in long-term care does not undermine it"

-Elder law expert Nina Kohn on the Nursing Home 411 Podcast



Listen to LTCCC's interview with Nina Kohn on the Nursing Home 411 Podcast <u>nursinghome411.org/podcast/voting-</u> <u>nursing-home/</u>

# How Can We Protect Residents' Voting Rights?

### **Voting Resources for Long-Term Care Residents**

Home / Voting Resources for Long-Term Care Residents

#### 🔅 WATCH LTCCC'S WEBINAR ON LTC VOTING RIGHTS

Voting rights are a fundamental right for residents in long-term care. According to federal rules for nursing homes, facilities must protect residents' rights as U.S. citizens and must support residents in the exercise of their rights.

Unfortunately, the COVID-19 pandemic is heightening barriers that have long interfered with residents' voting rights. This page includes links to fact sheets and resources containing information that can help preserve residents' essential rights to voting this election.

LTCCC's alert on protecting voting rights is available at nursinghome411.org/protect-residents-voting. NH411 PODCAST ON VOTING BARRIERS FOR LTC RESIDENTS

REGISTER TO VOTE IN PERSON OR BY MAIL (VOTE.ORG)

HOW TO VOTE IN YOUR STATE (THE WASHINGTON POST)

ASSISTING COGNITIVELY IMPAIRED INDIVIDUALS WITH VOTING (ABA)

COGNITIVE IMPAIRMENT AND VOTING (CONSUMER VOICE)

HOW TO CAST A VOTE (CONSUMER VOICE)

Voting resources available at <u>NursingHome411.org/voting</u>

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# Voting Resources: Vote.org

- Election Day is Tuesday November
  3, but you can take action before!
- Vote.org

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- Information on registration and voting (in-person or mail in) for every U.S. State
- COVID-19 voting information at <u>https://www.vote.org/covid-19/</u>
- Absentee voting: There is still time to vote by absentee ballot in all states. See

https://www.vote.org/absenteeballot-deadlines/ for state-specific information



#### CHECK YOUR REGISTRATION-

Not sure if you're registered to vote? We'll help you check and register if you can.



#### **REGISTER TO VOTE** $\rightarrow$

It takes less than 2 minutes to register.

#### VOTE BY MAIL $\rightarrow$

Can't or don't want to vote in person on Election Day? Request an absentee ballot.

#### GET ELECTION REMINDERS-

We'll remind you when and what you need to vote, so that you never miss an election again.

It's NOT too late!

## Residents Rights...

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# Visitation

# + Visitation: "Normal" Federal Rules

### A facility must meet the following requirements:

(A) Inform each resident (or resident representative, where appropriate) of his or her visitation rights and related facility policy and procedures, including any clinical or safety restriction or limitation on such rights, consistent with the requirements of this subpart, the reasons for the restriction or limitation, and to whom the restrictions apply, when he or she is informed of his or her other rights under this section.

(B) Inform each resident of the right, subject to his or her consent, to receive the visitors whom he or she designates, including, but not limited to, a spouse (including a same-sex spouse), a domestic partner (including a same-sex domestic partner), another family member, or a friend, and his or her right to withdraw or deny such consent at any time.

(C) Not restrict, limit, or otherwise deny visitation privileges on the basis of race, color, national origin, religion, sex, gender identity, sexual orientation, or disability.

(D) Ensure that all visitors enjoy full and equal visitation privileges consistent with resident preferences.

## Federal Rules

- March 13: Facilities should restrict visitation of all visitors and non-essential health care personnel, except for certain compassionate care situations, such as an end-of-life situation.
- May 18: Nursing home reopening "recommendations": Given the critical importance in limiting COVID-19 exposure in nursing homes, decisions on relaxing restrictions should be made with careful review of a number of facility-level, community, and State factors/orders.... ...State and local leaders should regularly monitor the factors for reopening and adjust their plans accordingly.
- June: FAQ on Nursing Home Visitation:
  - No new cases in facility for 28 days
  - No staff shortages
  - > Adequate access to testing
  - Local hospital capacity

## Visitation During the COVID-19 Pandemic **Compassionate Care Visitation**

While end-of-life situations were used as examples of compassionate care situations in previous CMS memoranda, the term "compassionate care situations" does not exclusively refer to end-of-life situations.

For example, for a resident who was living with their family before recently being admitted to a nursing home, the change in their environment and sudden lack of family can be a traumatic experience. Allowing a visit from a family member in this situation would be consistent with the intent of the term "compassionate care situations."

Similarly, allowing someone to visit a resident whose friend or family member recently passed away, would also be consistent with the intent of these situations.

### **Current** Federal Rules

- Visitation can be conducted through different means based on a facility's structure and residents' needs, such as in resident rooms, dedicated visitation spaces, outdoors, and for circumstances beyond compassionate care situations.
- Core principles include:
  - Screening for symptoms

- Face covering
- Social distancing

Hand hygiene

- Cleaning & disinfecting surfaces
- [V]isitation should be person-centered, consider the residents' physical, mental, and psychosocial well-being, and support their quality of life.
- The risk of transmission can be further reduced through the use of physical barriers (e.g., clear Plexiglas dividers, curtains).
- Also, nursing homes should enable visits to be conducted with an adequate degree of privacy.

### *Current* Federal Rules: Outdoor Visitation

**Outdoor visitation preferred**. Facilities should create accessible and safe outdoor spaces for visitation, such as in courtyards, patios, or parking lots, including the use of tents, if available.

### Money for facilities to facilitate

visitation. CMS will now approve the use of CMP funds [grants of up to \$3,000] to purchase tents for outdoor visitation and/or clear dividers (e.g., Plexiglas or similar product) to create a physical barrier to reduce the risk of transmission during in-person visits.



### *Current* Federal Rules: Indoor Visitation

Facilities should accommodate and support indoor visitation, including visits for reasons beyond compassionate care situations, based on the following guidelines:

- a) There has been no new onset of COVID-19 cases in the last 14 days and the facility is not currently conducting outbreak testing;
- b) Visitors should be able to adhere to the core principles and staff should provide monitoring for those who may have difficulty adhering to core principles...;
- c) Facilities should limit the number of visitors per resident at one time and limit the total number of visitors in the facility at one time (based on the size of the building and physical space). Facilities should consider scheduling visits for a specified length of time to help ensure all residents are able to receive visitors; and
- d) Facilities should limit movement in the facility. For example, visitors should not walk around different halls of the facility. Rather, they should go directly to the resident's room or designated visitation area. Visits for residents who share a room should not be conducted in the resident's room.

### + Visitation: Recommendations & Resources

### **Joint Recommendations**

- All residents access to visitors
- Pre-visit screening
- Read more <u>https://nursinghome411.org/recommend</u> <u>ations-visitation-sept2020/</u>

## LTCCC's Blueprint for restoring visitation rights

- Every resident has the right to designate at least one Support Visitor in Person (SVIP)
- Safe and reasonable accommodations
- Read more <u>https://nursinghome411.org/wp-</u> <u>content/uploads/2020/06/LTCCC-</u> <u>Statement-Let-Our-People-In.pdf</u>

### Forbes

EDITORS' PICK | 4,656 views | Oct 8, 2020, 11:15am EDT

### An Inside Look At How Covid-19 Is Driving An Epidemic Of Loneliness In Nursing Homes



Howard Gleckman Senior Contributor <sup>①</sup> Personal Finance I cover tax, budget and retirement policy from Washington



### Advocacy tips

The pandemic has been extremely dangerous, frightening, and heartbreaking for residents and their families.

Much of this, we believe, could have been avoided or ameliorated.

The challenges to resident advocacy for visitation and other issues have been daunting.

It is important to know that you are not alone, and that your voice and advocacy can make a difference!

- Think ahead about how you are going to see your loved one for Thanksgiving and the holidays. It might be better to make arrangements to visit on the day before or after a holiday, to avoid "the rush" and be able to spend more time, safely.
- Focus on right to compassionate care visitation. To make the case, focus on any indications of clinical or psycho-social decline.
- Know and iterate your rights about visitation. There are no limits on compassionate care visits. There is no basis for allocating only one visit per resident.
- Residents have the right to privacy during visits.
- Speak out!
  - State & Federal Legislators:
  - https://openstates.org/

https://www.congress.gov/contact-us

Governor's Office:

https://www.usa.gov/state-governor

CMS Regional Office:

https://nursinghome411.org/cmscontacts-regional-central-office-2019/



Residents Rights...

Information & Communication

### + Resident Records

The resident has the right to access personal and medical records pertaining to him or herself.

Access The facility must provide the resident with access to personal and medical records pertaining to him or herself, upon an oral or written request, in the form and format requested by the individual, if it is readily producible in such form and format (including in an electronic form or format when such records are maintained electronically); or, if not, in a readable hard copy form or such other form and format as agreed to by the facility and the individual, within 24 hours (excluding weekends and holidays); and

### + Resident Records

The facility must allow the resident to obtain a copy of the records or any portions thereof (including in an electronic form or format when such records are maintained electronically) upon request and 2 working days advance notice to the facility. The facility may impose a reasonable, costbased fee on the provision of copies, provided that the fee includes only the cost of: (A) Labor...; (B) Supplies for creating the paper copy or electronic media if the individual requests that the electronic copy be provided on portable media; and (C) Postage, when the individual has requested the copy be mailed.



Communication with Protection & Advocacy Agencies

The facility must furnish to each resident a written description of legal rights which includes...

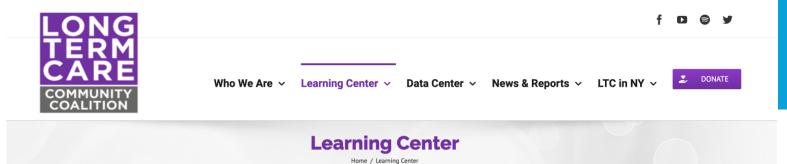
A list of names, addresses (mailing and email), and telephone numbers of all pertinent State regulatory and informational agencies, resident advocacy groups such as the State Survey Agency, the State licensure office, the State Long-Term Care Ombudsman program, the protection and advocacy agency, adult protective services where state law provides for jurisdiction in long-term care facilities, the local contact agency for information about returning to the community and the Medicaid Fraud Control Unit.

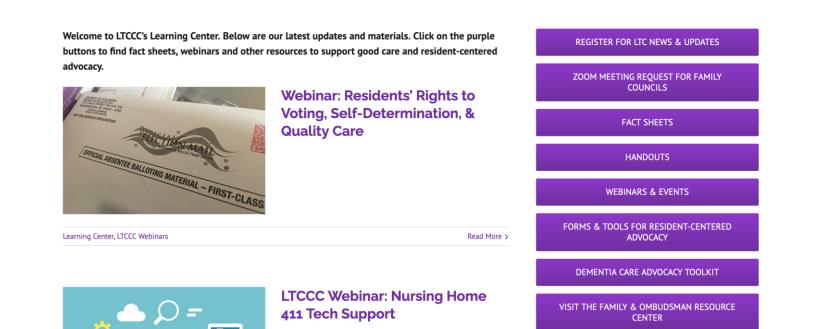
+ Communication with Protection & Advocacy Agencies

- A statement that the resident may file a complaint with the State Survey Agency concerning any suspected violation of state or federal nursing facility regulations, including but not limited to resident abuse, neglect, exploitation, misappropriation of resident property in the facility, non-compliance with the advance directives requirements and requests for information regarding returning to the community.
- Information and contact information for filing grievances or complaints concerning any suspected violation of state or federal nursing facility regulations, including but not limited to resident abuse, neglect, exploitation, misappropriation of resident property in the facility, non-compliance with the advance directives requirements and requests for information regarding returning to the community.

## Resources for Advocacy During the Pandemic & Beyond

## + Learning Center





### www.nursinghome411.org/learning-center/

## + Family & Ombudsman Resource Center

#### 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 or calling 212-385-0355.

You may also use LTCCC's Zoom video conference room to host family councils or family members meetings. Click here to request an appointment.

We would love to include you and support your efforts to improve care!

#### Joint Recommendations for Resident Visitation (September 2020)

#### Protect Voting Rights of Nursing Home Residents

More information on LTC voting is available at nursinghome411.org/voting. [...]

#### Nursing Home Care & The Coronavirus: This Is Not The

#### 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

#### FAMILY COUNCIL ZOOM MEETING REQUEST

FORMS & TOOLS FOR RESIDENT-CENTERED ADVOCACY

TELL YOUR STORY

UPCOMING WEBINAR PROGRAMS

WATCH PAST WEBINAR PROGRAMS



## + LTCCC's Primer & Fact Sheets

#### **Nursing Home Quality Standards**

#### A Primer for Residents, Families, Ombudsmen, and Advocates

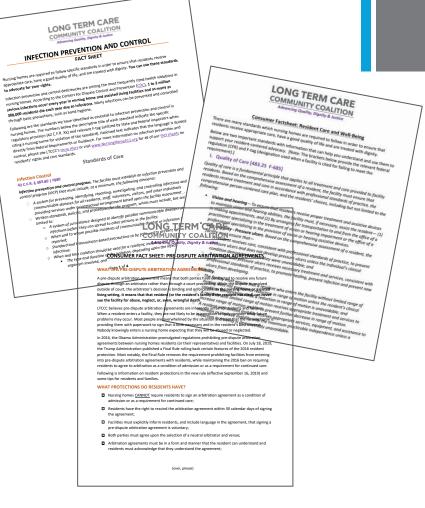


By Richard J. Mollot

#### Edited & Updated by Charles Gourgey Dara Valenejad

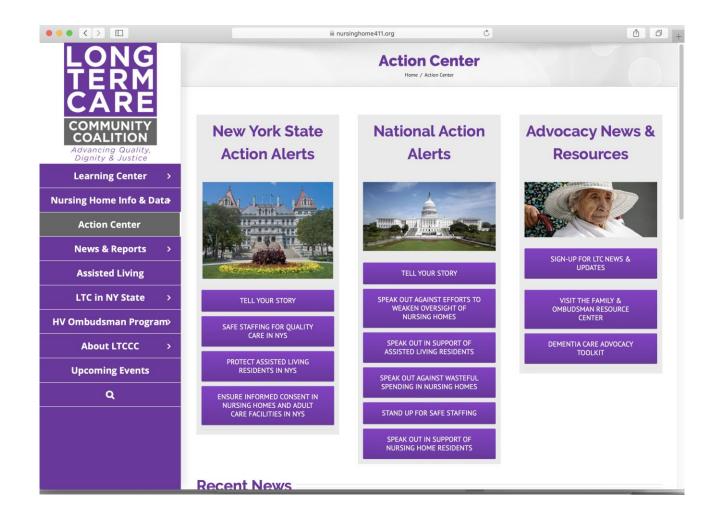
The Long Term Care Community Coalition One Penn Plaza, Suite 6252, New York, NY 10119 www.nursinghome411.org

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### www.nursinghome411.org

## + LTCCC Action Center



Contact your state and federal representatives and let them know that you are concerned about poor care, demeaning conditions, abuse, and neglect.

### www.nursinghome411.org/action-center/

# + Thank You For Joining Us Today!

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

Receive alerts for future programs or sign up for our newsletters. You can also...

- 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 <u>www.nursinghome411.org</u>.

### **UPCOMING PROGRAMS:**

- \* Wednesday, October 28 at 6pm: LTCCC Anniversary/Town Hall. Register now! <u>nursinghome411.org/event/30th</u>
- \* November 9: LTCCC Symposium: Identifying & Addressing Nursing Home Resident Abuse & Neglect
- \* **December 15: Webinar:** COVID-19 Update & Residents Rights: Family & Resident Councils, Filing Grievances

For more information & to register: <u>https://nursinghome411.org/events/</u>.

# See you at LTCCC's 30<sup>th</sup> Anniversary!

Celebrate LTCCC's 30th anniversary with a virtual town hall

### WHERE DO WE GO FROM HERE IN LONG TERM CARE?

October 28th • 6:00pm

Register nursinghome411.org/event/30th

## Featuring

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Richard N. Gottfried, Chair, NYS Assembly Health Committee Marcella Goheen, Family Member Cathy Unsino, LCSW, Advocate for Nursing Home Reform Judy Johnson, RN, Rutland Nursing Home



LTC Ombudsmen: If your program supervisor allows credit for attending this training program, please take the quick survey at: <u>https://www.surveymonkey.com/r/ltccc-ltcop1</u>.