



Focus on Residents'... Right to Vote, Right to Self-Determination, and Right to Equal Access to Quality Care

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: www.nursinghome411.org.

* Today's Agenda

- Update on COVID-19 data and policy developments.
- Residents' Rights...
 - ✓ Voting rights info & resources;
 - √ Self-determination; and
 - ✓ Access to quality care.
- Resources for advocacy now.

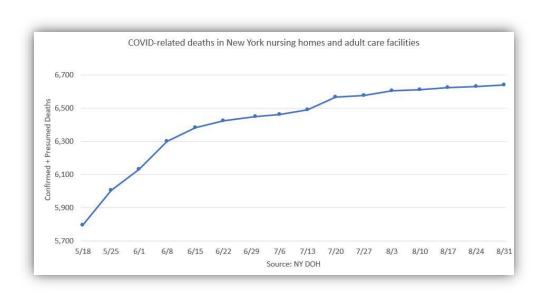
COVID-19 Update on Data and Policy Developments

COVID-19 Data Update: Rising LTC Cases & Fatalities

- Kaiser Family Foundation (September 4)
 - **468,607** COVID-19 cases (resident and staff) in **18,147** U.S. LTC facilities
 - **76,270** deaths
 - **30-day increase:** Approx. 100K cases, 10K deaths
- CMS (August 30)
 - **345,557** confirmed + suspected cases
 - **53,196** deaths
 - Significant state & regional variation
- NY DOH (August 31)
 - 6,639 LTC deaths in New York state
 - Continuing to plateau
 - https://nursinghome411.org/nynursinghome-covid-data/

CAUTION! Take data with a grain of salt.

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

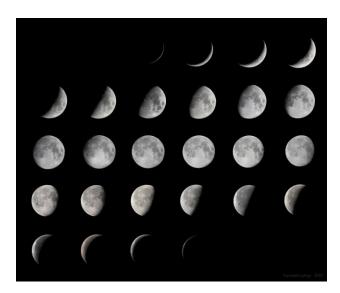




Visitation: Policy and Guidelines

- 186 days and counting
 - Easter, Passover, Ramadan, Memorial Day, July 4, Labor Day, Birthdays, Weddings, Anniversaries, Funerals....
- CMS reopening recommendations
 - 28 days with no new cases
 - Compassionate care
 - Not just end-of-life
 - No staff shortages
 - Sufficient PPE, Testing
 - Update (hopefully) coming soon...

- In New York
 - Pediatric Nursing Homes and Adult Care facilities resuming limited visitation
 - From 28 days to 14 days
 - Why not **all** nursing homes?



Visitation: Recommendations & Resources

Recommendations

- Outdoor/indoor visits for all residents (indoor if outdoor not possible)
- Inform residents, families, ombudsmen about policies
- Pre-visit screening
- All residents access to visitors
- Read more https://nursinghome411.org/recommenda tions-visitation-sept2020/

■ CANHR's Visitation Saves Lives Campaign

- Read more https://visitationsaveslives.com/
- Share your story on Social Media #VisitationSavesLives

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 https://nursinghome411.org/wpcontent/uploads/2020/06/LTCCC-Statement-Let-Our-People-In.pdf

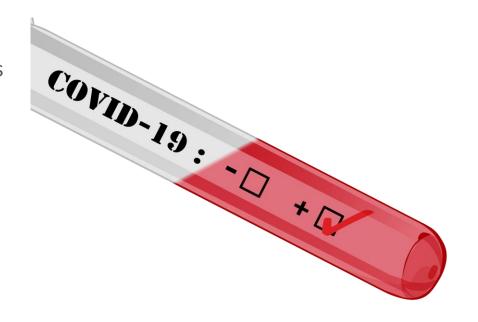


New Testing & Reporting Requirements

- Department of Health and Human Services (HHS): 750,000 COVID-19 point-of-care tests.
 - Fast 15-minute Abbott antigen tests
 - Free for facilities
 - Targeting facilities in counties designated as higher risk "red or yellow" by Centers for Medicare & Medicaid Services (CMS)

Still lacking long-term plan

- Concerns over supply chain
- Not supplied indefinitely; transition to free-market structure could be costly
- What's next?





Focus of Today's Discussion: Residents' Rights

Nursing Home Quality Standards

A Primer for Residents, Families, Ombudsmen, and Advocates





By Richard J. Mollo

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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1. General Residents' Rights [42 CFR 483.10, F-550]14

(a) The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility.

- (1) A facility must treat each resident with respect and dignity and care for each resident
 in a manner and in an environment that promotes maintenance or enhancement of his
 or her quality of life, recognizing each resident's individuality. The facility must protect
 and promote the rights of the resident.
- (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.
 - (1) The facility must ensure that the resident can exercise his or her rights without interference, coercion, discrimination, or reprisal from the facility.
 - (3) In the case of a resident who has not been adjudged incompetent by the state court, the resident has the right to designate a representative, in accordance with State law and any legal surrogate so designated may exercise the resident's rights to the extent provided by state law.
 - (5) The facility shall not extend the resident representative the right to make decisions on behalf of the resident beyond the extent required by the court or delegated by the resident.
 - (7) In the case of a resident adjudged incompetent... (ii) The resident's wishes and preferences must be considered in the exercise of rights by the representative.
- (d) The resident has the right to choose his or her attending physician.

Residents Rights...

Voting

* Who are the LTC Voters?

Meet Walter Hutchins

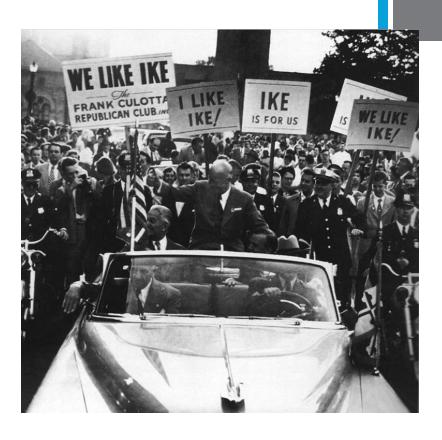
- Industrial Engineer, Inventor
- Helped design the M16
- Resident, Davis Community Nursing Home (NC)
- Blind, hard of hearing

■ Voted 68 consecutive years

- First vote: Dwight D. Eisenhower, 1952
- Fire stations, churches, their retirement community
- Blind, hard of hearing

■ Voting streak in jeopardy...

- State law (NC) prohibits staff from helping with ballots
- Visitors barred because of pandemic-related restrictions
- Wife Margaret, 4 kids, 8 grandchildren can't help
- Margaret: "It makes me angry that something like this could happen and that we'd be denied the right to vote just because of our age and condition"



Who are the LTC Voters?





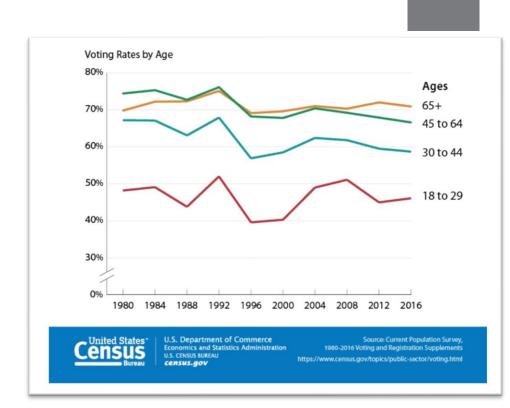
Visiting my 90 year-old dad, who is sadly nearing the end, and 84 year-old mom in Florida. Dad is pretty clear-eyed about his future and says he is "ready to go." But he has one thing he still wants to accomplish.

"I want to stay alive long enough to vote."

So proud of him.

Who are the LTC Voters?

- 2.2 million residents in a nursing home or residential care
 - Voting: A fundamental part of identity
- Older adults: 'the backbone of American elections'
 - In 2018, 66% of Americans 65+ voted vs. 35% among 18-29
 - Most impacted by COVID-19
- A non-partisan issue
 - Older adults (65+) more likely to vote Donald Trump (53%) than Hillary Clinton (44%), according to the Pew Research Center



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





Barriers: Disability & Environment

- Cognitive impairment
 - Doesn't necessarily preclude resident from voting (varies state to state)
 - Difficult to comply with voting processes but not impacting ability to make voting choice (i.e.. Shortterm memory loss)
- Physical disability
 - Reading ballot
 - Filling out forms
- Access to information
 - Registration
 - Deadlines

"People whose mental capacities are clearly intact may vote for candidates based on any whim or reason, rational or irrational, profound or frivolous."

- American Bar Association



'A Perfect Storm': COVID-19 & LTC Voting



- LTC voters already marginalized
 - Violations in previous election: no opportunity to vote or unable to get help casting a ballot
 - Categorized as low severity (little or no harm)
- 2020 Election: "Hundreds of Thousands of Nursing Home Residents May Not Be Able to Vote in November Because of the Pandemic" – ProPublica
 - Restrictions on visitors, ombudsmen
 - Suspended programs for election officials to enter facility
 - Lack of oversight
- Elder law expert Nina Kohn: "We're headed for a perfect storm unless there's a quick correction"

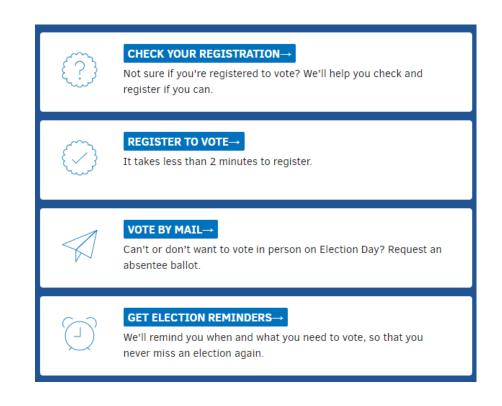


How Can We Protect Residents' Voting Rights?



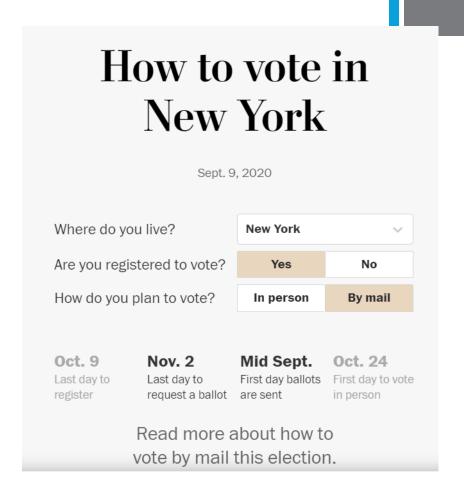
Voting Resources: Vote.org

- Vote.org
 - Information on registration and voting (in-person or mail in) for every U.S. State
 - For Vote.org's New York election page, visit https://www.vote.org/state/new-york/
 - COVID-19 voting information at https://www.vote.org/covid-19/



Voting Resources: How to Vote in Your State (Washington Post)

- https://www.washingtonpost.com/ele ctions/2020/how-to-vote/
 - Dates and deadlines for registration
 - Dates and deadlines for voting in person or by mail
 - **Every U.S. State**
 - New York Voters: https://www.washingtonpost.com/e lections/2020/how-to-vote/new-york/





Voting Resources: National Consumer Voice Fact Sheets

How to Cast a Vote

- Alternatives to traditional voting for consumers of long-term care
- Absentee voting
- Early voting
- Voting in facility
- Available at
 https://theconsumervoice.org/upl

 oads/files/events/How_to_Cast_a
 Vote final.pdf

Cognitive Impairment and Voting

- 'A complicated issue'
- Varies across states
- Legal restrictions Practical barriers
- Available at <u>https://theconsumervoice.org/uploads/files/issues/cognitive-impairment-voting.pdf</u>

Residents Rights...

Self-Determination



Self-Determination & Exercise of Rights

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

Fact Sheet: The Fundamentals of Resident Rights - Dignity & Respect

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 and community.

Following are two important federal standards. They apply to every nursing home resident in licensed facilities in the U.S. On the following page are some examples that illustrate how these standards are to be realized by nursing homes. [Note: The brackets below provide, for reference, the citation to the federal requirement (42 CFR 483.xx) and the F-tag number used when a facility is cited for failing to meet the requirement.]

STANDARD 1: RESIDENT RIGHTS [42 CFR 483.10(a) F-550]

- The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility....
- A facility must treat each resident with respect and dignity and care for each resident in a manner and in an environment that promotes maintenance or enhancement of his or her quality of life, recognizing each resident's individuality.
- The facility must protect and promote the rights of the resident.
- The facility must provide equal access to quality care regardless of diagnosis, severity of
 condition, or payment source. A facility must establish and maintain identical policies and
 practices regarding transfer, discharge, and the provision of services under the State plan for all
 residents regardless of payment source.

STANDARD 2: EXERCISE OF RIGHTS [42 CFR 483.10(a) F-550]

- 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.
- The facility must ensure that the resident can exercise his or her rights without interference, coercion, discrimination, or reprisal from the facility.
- 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.

INTENT OF THIS REGULATION

- Each resident has the right to be treated with dignity and respect. All staff activities and
 interactions with residents must focus on assisting the resident in maintaining and enhancing
 his or her self-esteem and self-worth and incorporating the resident's preferences and choices.
 Staff must respect each resident's individuality when providing care and services while honoring
 and valuing their input.
- All residents have rights guaranteed to them under Federal and State law and regulations. This
 regulation is intended to lay the foundation for the rights requirements. A resident must be
 allowed to exercise their rights based on his or her degree of capability.

Residents Rights...

Quality Care



All Residents Have the Right to the Same Quality of Care



20 Common Nursing Home Problems and How To Resolve Them

By Eric Carlson







20 Problems — and How to Resolve Them

Discrimination Against Medicaid-Eligible Residents

What You Hear: X



"Medicaid does not pay for the service that you want."

The Facts: 🔽



A Medicaid-eligible resident is entitled to the same level of service provided to any other nursing home resident.

The Nursing Home Reform Law prohibits discrimination based on a resident's Medicaid eligibility. A nursing home "must establish and maintain identical policies and practices regarding transfer, discharge, and the provision of services required under the State [Medicaid] plan for all individuals regardless of source of payment." (Section 483.12(c)(1) of Title 42 of the Code of Federal Regulations [emphasis added])

Nursing homes have a love-hate financial relationship with Medicaid. On one hand, approximately two-thirds of nursing home residents are Medicaid-eligible, and the Medicaid program accounts for approximately one-half of nursing homes' total revenues. On the other hand, Medicaid rates tend to be the lowest - lower than private-pay rates, and much lower than the rates paid by the Medicare program.

What to Do to Fight Medicaid Discrimination

A Medicaid-eligible resident should resist any attempt by the nursing home to give

her second-class treatment. She should emphasize the federal law (quoted above) that prohibits a nursing home from discriminating against Medicaid-eligible residents.

Nursing home staff members are quick to claim – generally without proof – that the nursing home loses money on each Medicaid-eligible resident. A resident should avoid getting drawn into a discussion of the nursing home's financial status. There is no way to win the argument without a detailed audit of the nursing home and any related corporations.

A better strategy is to assume that the nursing home's finances are irrelevant as, indeed, they are in this situation. By seeking Medicaid certification, a nursing home promises the federal and state governments that it will provide Medicaid-eligible residents with the care guaranteed by the Nursing Home Reform Law. It is completely hypocritical for the nursing home to accept Medicaid money for a resident's care, and then turn around and tell the resident that the care will be inadequate because Medicaid payment rates are low.

+ LTCCC Factsheet: Resident Care & Well-Being



Advancina Quality, Dianity & Justice

Consumer Factsheet: Resident Care and Well-Being

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.

Below are two important standards with information that can help you understand and use them to support your resident-centered advocacy. [Note: The brackets below provide the relevant federal regulation (CFR) and F-tag (designation used when a facility is cited for failing to meet the requirement).]

I. Quality of Care [483.25 F-685]

Quality of care is a fundamental principle that applies to all treatment and care provided to facility residents. Based on the comprehensive assessment of a resident, the facility must ensure that residents receive treatment and care in accordance with professional standards of practice, the comprehensive person-centered care plan, and the residents' choices, including but not limited to the following:

- Vision and hearing To ensure that residents receive proper treatment and assistive devices to maintain vision and hearing abilities, the facility must, if necessary, assist the resident (1) In making appointments, and (2) By arranging for transportation to and from the office of a practitioner specializing in the treatment of vision or hearing impairment or the office of a professional specializing in the provision of vision or hearing assistive devices.
- Skin Integrity Pressure ulcers. Based on the comprehensive assessment of a resident, the facility must ensure that—
 - A resident receives care, consistent with professional standards of practice, to prevent pressure ulcers and does not develop pressure ulcers unless the individual's clinical condition demonstrates that they were unavoidable; and
 - A resident with pressure ulcers receives necessary treatment and services, consistent with professional standards of practice, to promote healing, prevent infection and prevent new ulcers from developing.

Mobility.

- The facility must ensure that a resident who enters the facility without limited range of motion does not experience reduction in range of motion unless the resident's clinical condition demonstrates that a reduction in range of motion is unavoidable; and
- A resident with limited range of motion receives appropriate treatment and services to increase range of motion and/or to prevent further decrease in range of motion.
- A resident with limited mobility receives appropriate services, equipment, and assistance to maintain or improve mobility with the maximum practicable independence unless a reduction in mobility is demonstrably unavoidable.

 Incontinence. The facility must ensure that resident who is continent of bladder and bowel on admission receives services and assistance to maintain continence unless his or her clinical condition is or becomes such that continence is not possible to maintain.

II. Activities of Daily Living [483.24(a) F-676]

- Based on the comprehensive assessment of a resident and consistent with the resident's needs
 and choices, the facility must provide the necessary care and services to ensure that a
 resident's abilities in activities of daily living do not diminish unless circumstances of the
 individual's clinical condition demonstrate that such diminution was unavoidable. This includes
 the facility ensurina that:
 - A resident is given the appropriate treatment and services to maintain or improve his or her ability to carry out the activities of daily living...
- Activities of daily living. The facility must provide care and services... for the following activities of daily living:
 - o Hygiene -bathing, dressing, grooming, and oral care,
 - Mobility—transfer and ambulation, including walking,
 - Elimination—toileting,
 - Dining—eating, including meals and snacks,
 - Communication, including (i) Speech, (ii) Language, (iii) Other functional communication systems.

MAINTAINING PHYSICAL & EMOTIONAL WELL-BEING: CHECKLIST

EVERY residents has the right to receive the care and services he or she needs to reach and maintain his or her highest possible level of functioning and well-being. Following are some relevant points to keep in mind:

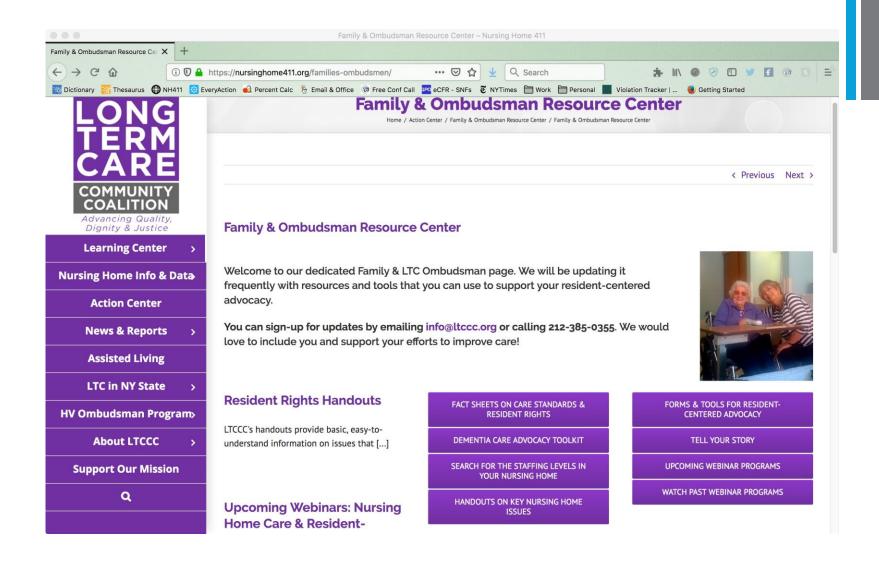
- Bathing, dressing and grooming (in accordance with the resident's preferences & customs).
- Toileting (including assistance to get to and from the bathroom in a timely manner).
- Ability to walk (including with assistance from an aide or using an assistive device).
- No development of pressure ulcers unless unavoidable as a result of resident's clinical condition.

 Items in the resident assessmen 	t, care plan or that i	are important to you:
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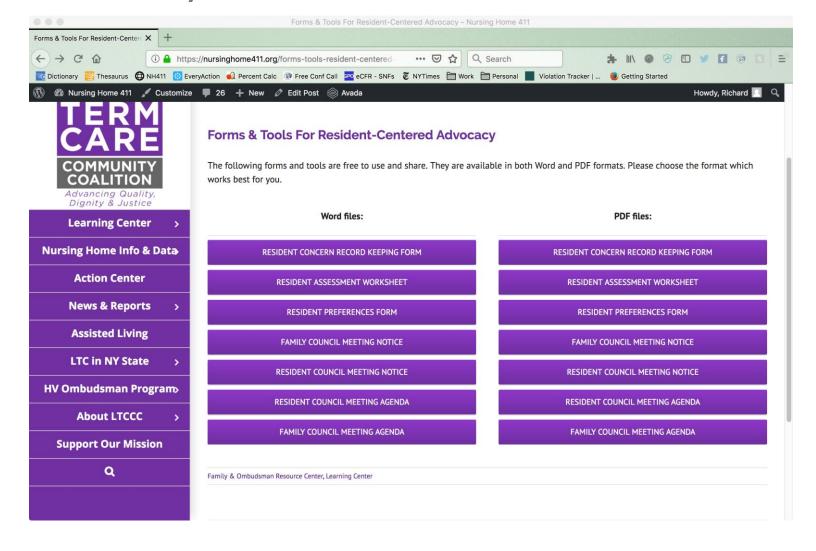
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Resources for Advocacy During the Pandemic & Beyond

+ Family & Ombudsman Resource Center



+ Forms & Tools for Resident-Centered Advocacy



+ 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.

	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:	Spouse or partner Friends Children Grandchildren	
My birthday is: (Write N/A if you prefer	Other	
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:	□ Now	
Favorite food:	☐ In the past	
Animals I like:	Dogs Cats Other: Idon't care for animals	_

+ 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 Invo	lved or Witnesses (if any):		
Staff Persor	n(s) Spoken To:		
Response/P	Plan of Action from Staff:		
Response/P	lan of Action from Staff:		
Response/P	lan of Action from Staff:		
Response/F	Plan of Action from Staff:		
Response/F	Plan of Action from Staff:		
Response/P			

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....

+ 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.

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.

Next Program: October 20 at 1pm.

Topics: COVID-19 Update & Residents Rights Advocacy During the Pandemic.

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>.

Questions? Comments?

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