

LTCCC FAMILY COUNCIL TOOLKIT

RESOURCES TO EMPOWER YOUR
RESIDENT-CENTERED ADVOCACY



NursingHome411.org/families



families@ltccc.org



212-385-0355

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

Greetings,

My name is Jenine Ferrari and I'm the nursing home family council liaison with the **Long Term Care Community Coalition (LTCCC)**. I'm reaching out to ask for your help in sharing some of our relevant resources with the families you encounter in your work.

My experience with family councils began at the start of the COVID-19 pandemic. My dad is a veteran who lives in a nursing home. For months, because of visitation restrictions, I couldn't see him. I felt left out, isolated, and starved for information, without meaningful communication efforts from the nursing home. Because of his dementia, my dad couldn't understand why I couldn't visit and hearing the disappointment in his voice just killed me.

After speaking to other families from my dad's nursing home, I learned I wasn't alone. In September 2020, family members began holding weekly informational meetings using **LTCCC's free Family Council Zoom Room**. We didn't realize it at the time, but these meetings marked the formation of our nursing home family council. In these virtual sessions, we discuss the challenges facing our loved ones, vent about our shared frustrations in lockdown, and work together on ways to improve care and conditions for our residents.

Now 20 months old and with 100-plus members, the family council is making a difference in the lives of residents. We're empowered to advocate for individual and systemic change. We're communicating more effectively with staff and administration, leading to better resident care. We're breaking down barriers to visitation so that we can see and care for our loved ones.

Let's Chat!



families@ltccc.org



212-385-0355

Families and residents deserve to have the same opportunity as we've had. In my role as family council liaison with LTCCC, I am here to help families make that happen.

Let's empower families so that nursing home residents get the care they deserve!

Enclosed are a few useful resources for families and those who work with them, including a fact sheet for family and resident councils, forms & tools for resident-centered advocacy, and my personal favorite, the resident care planning handout. We would appreciate your help in distributing the materials to families in your area. These resources, and many others, are available for free in the Learning Center of LTCCC's website, **www.nursinghome411.org**.

Please feel free to reach out to me at **families@ltccc.org** or **212-385-0355** if you have any questions or if we can provide you with more information and resources for families of nursing home residents.

Sincerely,

Jenine Ferrari

Family Council Liaison

Long Term Care Community Coalition

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CONSUMER FACT SHEET: RESIDENT & FAMILY COUNCILS

Resident and Family Councils can play a very important role in improving care and quality of life in a nursing home. However, residents and families can face challenges in respect to organizing and meeting in a way that is independent of the facility staff and enables them to make their voices heard.

The new federal nursing home standards clarify and strengthen requirements for nursing home Resident & Family Councils. Following are relevant provisions in the regulations that you can use to support a vibrant and effective Resident or Family Council in your nursing home.

Please note: (1) Text in italics is directly from the federal regulations. (2) Brackets provide references to the federal regulations and the F-tag number (used when a facility is cited for failing to meet the requirement). (3) These standards are applicable to all residents in licensed nursing homes in the United States, whether they are short-term or long-term, private pay, Medicaid, Medicare or have another type of insurance. (4) Where the resident lacks capacity to make decisions and/or has assigned decision-making to someone else, that person takes the place of the resident in exercising these rights.

What is a Resident or Family Council?

The new federal regulations specify that residents and families have the right to join together to:

- Discuss and offer suggestions about facility policies and procedures affecting residents' care, treatment, and quality of life;
- Support each other;
- Plan resident and family activities;
- Participate in educational activities; or
- For any other purpose.

THE LAW

I. Resident & Family Councils [CFR 483.10(f)(5) F-565]

The resident has a right to organize and participate in resident groups in the facility.

- *The facility must provide a resident or family group, if one exists, with private space; and take reasonable steps, with the approval of the group, to make residents and family members aware of upcoming meetings in a timely manner.*
- *The resident has a right to participate in family groups.*
- *The resident has a right to have family member(s) or other resident representative(s) meet in the facility with the families or resident representative(s) of other residents in the facility.*

- *Staff, visitors, or other guests may attend resident group or family group meetings only at the respective group's invitation.*

II. Facility Responsibilities for Resident & Family Councils

- *The facility must provide a designated staff person who is approved by the resident or family group and the facility and who is responsible for providing assistance and responding to written requests that result from group meetings.*
- *The facility must consider the views of a resident or family group and act promptly upon the grievances and recommendations of such groups concerning issues of resident care and life in the facility.*
 - *The facility must be able to demonstrate their response and rationale for such response.*
 - *This should not be construed to mean that the facility must implement as recommended every request of the resident or family group.*

Considerations for Resident-Centered Advocacy

- Residents and families have the right to form and participate in a Council.
- Residents have the right to be a member of the Family Council and to decide if their family member or other designee participates in a Family Council.
- Nursing homes are required to provide a private space for Council meetings and can only have a staff person in attendance if he or she is invited by the Council.
- The nursing home must have a designated staff person who has been approved by the Council and is responsible for providing assistance to the Council and responding to written requests from the Council.
- Nursing homes must consider the Council's concerns and recommendations. While they are not obliged to do everything that the Council wants, nursing homes are required to demonstrate their response to the Council's concerns and recommendations and provide a rationale for their response.
- When the state surveyors come for an inspection they should be interviewing representatives from Resident and Family Councils to determine if these requirements are being fulfilled. For example, they should ask:
 - How are views, grievances or recommendations from the Council considered, addressed and acted upon? and
 - How do facility staff provide responses, actions, and rationales to the Council?

RESOURCES

- WWW.NURSINGHOME411.ORG. LTCCC's website includes a variety of resources to support resident-centered advocacy, including all of our webinar programs and fact sheets.
- WWW.THECONSUMERVOICE.ORG. The Consumer Voice has numerous materials and resources for residents, family members and LTC Ombudsmen, including substantial resources on developing and empowering a family council.

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Consumer Fact Sheet: 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 ensuring 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:*
 - *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 resident 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 assessment, care plan or that are important to you:
 - _____
 - _____
 - _____
 - _____

RESOURCES

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.

LONG TERM CARE COMMUNITY COALITION

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CONSUMER FACT SHEET: RESIDENT 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. The purpose of these factsheets is to provide relevant language from the standards and information that **YOU** can use to support your resident-centered advocacy.

Following is the language from the federal requirements for resident care planning in nursing homes. [Note: The brackets provide the relevant federal regulation (CFR) and F-tag (category of deficiency).]

IMPORTANT NOTES: The new federal nursing home standards greatly expand expectations for care planning. This was done to help ensure that they are more resident-focused and establish plans of care that are appropriate for each resident's individual needs. These changes are being implemented over three phases: November 2016, November 2017 and November 2019. Effective dates are indicated for each provision presented below.

Please also see the "LTCCC Factsheet Resident Assessment Care Planning" for information on resident assessment requirements, which are fundamental to care planning. It is available at www.nursinghome411.org.

I. COMPREHENSIVE PERSON-CENTERED CARE PLANNING [42 CFR 483.21(b) F-656]¹

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. [Emphasis added.]

A comprehensive care plan must be—

- *Developed within 7 days after completion of the comprehensive assessment.*
- *Prepared by an interdisciplinary team, that includes but is not limited to—*
 - *The attending physician.*
 - *A registered nurse with responsibility for the resident.*
 - *A nurse aide with responsibility for the resident.*
 - *A member of food and nutrition services staff.*
 - *To the extent practicable, the participation of the resident and the resident's representative(s). An explanation must be included in a resident's medical record if the*

¹ Effective November 2016.

participation of the resident and their resident representative is determined not practicable for the development of the resident's care plan.

- *Other appropriate staff or professionals in disciplines as determined by the resident's needs or as requested by the resident.*
- *Reviewed and revised by the interdisciplinary team after each assessment, including both the comprehensive and quarterly review assessments.*

*The services provided or arranged by the facility, as outlined by the comprehensive care plan, must—
...Meet professional standards of quality.*

The services... outlined by the comprehensive care plan, must—

- *Be provided by qualified persons in accordance with each resident's written plan of care.*
- *Be culturally-competent and trauma-informed.²*

II. Baseline Care Plans³

The facility must develop and implement a baseline care plan for each resident that includes the instructions needed to provide effective and person-centered care of the resident that meet professional standards of quality care. The baseline care plan must--

- *Be developed within 48 hours of a resident's admission.*
- *Include the minimum healthcare information necessary to properly care for a resident including, but not limited to—*
 - *Initial goals based on admission orders.*

Physician orders, Dietary orders, Therapy services, Social services [and] PASARR [Preadmission Screening and Resident Review] recommendation, if applicable.

Requirements for the Comprehensive Care Plan

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...*

² Trauma-informed effective November 2019.

³ Effective November 2017.

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CONSUMER FACT SHEET: PRESSURE ULCERS

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.

Following is the standard and guidelines that we have identified as essential when it comes to pressure ulcers in nursing homes. The descriptions were taken directly from the federal regulations and guidelines (as indicated by text in *italics*). For more information about pressure ulcers, please see LTCCC's [issue alert](#).

THE LAW

Skin Integrity [42 C.F.R. § 483.25(b)(1)] [F-686]

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.*

WHAT IS A PRESSURE ULCER?

Pressure ulcers occur when there is damage to a resident's skin or underlying tissue. Pressure ulcers are generally localized to areas of the body with bony prominences that absorb pressure from prolonged immobility (such as elbows, hips, heels, and shoulders). Pressure ulcers are classified into stages, based on the severity of the injury.

WHAT DOES "UNAVOIDABLE" MEAN?

According to CMS's Interpretative Guidance, "unavoidable" means that a pressure ulcer formed *even though the facility had evaluated the resident's clinical condition and risk factors; defined and implemented interventions that are consistent with resident needs, goals, and professional standards of practice; monitored and evaluated the impact of the interventions; and revised the approaches as appropriate.*

For additional information and resource, please visit nursinghome411.org

HOW CAN PRESSURE ULCERS BE PREVENTED AND TREATED?

CMS's Guidance states that *[e]ffective prevention and treatment are based upon consistently providing **routine and individualized** interventions*, including:

- Redistributing pressure, such as through *repositioning, protecting and/or offloading heels, etc.*;
- Minimizing the resident's exposure to moisture and keeping the resident's skin clean;
- Providing support and non-irritating surfaces; and
- Maintaining or improving the resident's nutrition and hydration status, including addressing adverse drug reactions which *may worsen risk factors for development of, or for non-healing PU/PIs [pressure ulcers]* . . .

CAN RESIDENTS PARTICIPATE IN THEIR CARE PLANNING?

Yes! The resident's care plan should establish relevant goals, approaches, and interventions for addressing the resident's risk of developing a pressure ulcer. CMS's Guidance notes that, *[i]n order for the resident to **exercise his or her right appropriately to make informed choices about care and treatment or to decline treatment**, the facility and the resident (or if applicable, the resident representative) must discuss the resident's condition, treatment options, expected outcomes, and consequences of refusing treatment*. If a resident determines not to undertake one form of prevention or treatment, *[t]he facility is expected to address the resident's concerns and offer relevant alternatives* . . .

For more information, please see LTCCC's [fact sheet on resident assessment](#) and care planning at www.nursinghome411.org.

A BRIEF NOTE ABOUT ABUSE AND NEGLECT

Pressure ulcers may be a sign of resident abuse and/or neglect. **Under the federal Nursing Home Reform Law, every nursing home resident has the [right to be free from abuse and neglect](#)**. CMS's Interpretative Guidance for this requirement notes that abuse may include the *deprivation by staff of goods or services that are necessary to attain or maintain physical, mental, and psychosocial well-being*. Similarly, CMS states that neglect may occur, *[i]f the facility is aware of, or should have been aware of, goods or services that a resident(s) requires but the facility fails to provide them to the resident(s)*.

Federal law and regulations require nursing homes to report all alleged violations of abuse and neglect to the facility administrator and the state survey agency *immediately, but not later than 2 hours after the allegation is made, if the events that cause the allegation involve abuse or result in serious bodily injury, or not later than 24 hours if the events that cause the allegation do not involve abuse and do not result in serious bodily injury*. For more information about resident abuse and neglect, please see LTCCC's [Abuse, Neglect, and Crime Reporting Center](#) at www.nursinghome411.org.

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FAMILY COUNCIL MEETING NOTICE

WHEN IS THE NEXT MEETING?

Date:

_____.

Time:

_____AM/PM.

Location:

_____.

WHY SHOULD I PARTICIPATE?

Family councils play an important role in improving quality of care and quality of life in nursing homes. Family councils offer participants a safe space to share concerns, seek support from one another, and exchange information about residents' rights and protections. Your participation gives our family council a unified voice in addressing the needs of residents.

WHAT ARE MY RIGHTS?

Under federal law, every nursing home must protect and promote the right of a resident's family or representative "to meet in the facility with the families of other residents"

This means:

- ☐ The facility must provide our family council a private meeting space and notify families and residents of upcoming meetings in a timely manner;
- ☐ The facility must designate, with our approval, a staff member to assist our council and respond to requests;
- ☐ The facility must promptly respond to our concerns, grievances, and recommendations; and
- ☐ Guests (including staff or other non-residents) are only allowed to attend our meetings if invited.

Please use the back of this notice to note concerns you would like to raise at our next meeting. You can bring it with you to the meeting or, if you are unable to attend, have another family member, resident, invited guest, or designated staff member bring it to the meeting.

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DATE:	NAME (OPTIONAL):
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I would like to raise the following concerns at the family council meeting:

ADDITIONAL RESOURCES

Visit www.nursinghome411.com for free resources on residents' rights and tools that you can use to support your resident-centered advocacy.

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)

6. Committee Reports and Updates

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

8. Action Items (if any)

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

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

9. Confirmation of Next Meeting and Adjournment

**ADDITIONAL
RESOURCES**

Visit www.nursinghome411.com for free resources on residents' rights and tools that you can use to support your resident-centered advocacy.

ADDITIONAL RESOURCES

FOR MORE INFO, CHECK OUT THE FOLLOWING:

LTCCC Family & Ombudsman Resource Center:

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

Forms and Tools for resident-centered advocacy:

<https://nursinghome411.org/forms-advocacy/>

LTCCC YouTube/Webinars:

<https://www.youtube.com/longtermcarecommunitycoalition>

LTCCC Data Center:

<http://nursinghome411.org/data>

Long-Term Care in New York:

<http://nursinghome411.org/ny>

NursingHome411 Podcast:

<http://nursinghome411.org/podcast>

Fact Sheet Center:

<https://nursinghome411.org/facts>

LTCCC Learning Center:

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

Get LTCCC's latest news and resources for FREE at [NursingHome411.org/join](https://nursinghome411.org/join) or scan the QR code below:

To use the QR code:

- 1 Open your camera and point your device at the QR code
- 2 Wait for camera to scan and recognize the QR code
- 3 Click the banner or notification when it appears on your screen
- 4 The website will automatically load. Enjoy browsing!



CONTACT US:



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212-385-0355



To sign up for a family council Zoom room, please visit: bit.ly/fam-council-room