



The National

CONSUMER VOICE

for Quality Long-Term Care

formerly NCCNHR

Family Advocacy for Residents During COVID

How would you describe your primary role:

- Family member of a nursing home resident/assisted living facility resident/individual receiving services at home
- Resident of a nursing home/assisted living facility/individual receiving services at home
- Long-term care ombudsman
- Individual citizen advocate
- Member of a citizen advocacy group
- Other

Agenda

I. How to advocate on behalf of a loved one and other residents

- Individually
- Through a Family Council
- Long-Term Care Ombudsman Program

II. Common Situations

- Visitation
- Transfers/discharges
- Going outside/leaving the facility
- Transparency
- Testing

III. Advocating Together

IV. Q&A/discussion

Residents' Rights

Despite the pandemic, residents still have the right to:

- Receive care and services to obtain highest level of well-being
- Participate in the development and implementation of a person-centered plan of care, including the right to make decisions about care now and in the future
- Be free from abuse, neglect, exploitation, and misappropriation of property
- Voice grievances without discrimination or retaliation and prompt efforts by the facility to solve their grievances

INDIVIDUAL ADVOCACY

What can you do to help your family member?

Individual Advocacy

Work with your facility!

- Speak regularly with administration and staff
- Ask what they are doing to keep residents safe
- Insist on regular updates to all families
- Care planning conference
- File a grievance with the facility

Individual Advocacy

Ombudsmen

- Contact the ombudsman program in your state to assist you
https://theconsumervoice.org/get_help

State Survey Agency

- Limited BUT still file complaints

Elected Officials

- They need to know what's happening in their district/state
<https://www.house.gov/representatives/find-your-representative>

Media

- Write letters to the editor, reach out to local media, use social media

Individual Advocacy

Share Your Story:

<https://theconsumervoice.org/issues/other-issues-and-resources/covid-19/residents-families/share-your-story>

Advocating Through a Family Council



What a Family Council Is

A **self-led self-determining** group of families and friends of nursing home residents that:

- Works to improve the quality of care and quality of life of the facility's residents; and
- Provides families with a voice in decision-making that affects them and their loved ones.

What Family Councils Do

- Act on concerns and complaints affecting nursing home residents
- Advocate for positive change within the facility and the long-term care system
- Communicate with the nursing home administrator and staff
- Serve as a sounding board and advisory body on new ideas and improvements
- Educate and inform families about issues relating to residents, the nursing home, and the long-term care system
- Provide support to family members

Family Council Rights

- A resident's family has the right to meet in the facility with the families of other residents in the facility.
- The facility must provide a family group, if one exists, with private space.
- Staff or visitors may attend meetings only at the group's invitation.
- The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings.
 - Staff person must be approved by the family group and the facility
- When a family group exists, the facility must listen to the views and act upon the grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility.
 - The facility must be able to demonstrate their response and rationale for such response.
 - This does not mean the facility must implement as recommended every request of the family group.

Starting a Family Council

- Find out if there is a family council in your loved one's facility
- If not, start one!
 - Develop a flyer announcing the formation of a family council; put your name and contact information on it
 - Ask the administrator to send your flyer to family members
 - Contact the Long-Term Care Ombudsman Program for assistance
 - Create a Facebook group to attract family members; communicate directly with them about forming a family council
 - Be creative and innovative:
 - One family member handed out flyers at the facility's laundry pick up/drop off area.

Build Your Family Council: Resources

Long-Term Care Ombudsman Program



Consumer Voice Family Council Center

Specialized Information for:

- Long-Term Care Consumers
- Family Members
- Advocates
- COVID-19

Family Council Center

Family members in a nursing home can join together to form a united consumer voice which can communicate concerns to facility administrators and work for resolutions and improvements by forming a family council. Family councils can play a crucial role in voicing concerns, requesting improvements, supporting new family members and residents, and supporting facility efforts to make care and life in the facility the best it can be.

Join and support the family council at your loved one's facility! If no family council exists, join with other family members to form one.

This family council center contains factsheets and other materials related to family council creation, maintenance, rights under federal law and advocacy. It also has information about family council grants, networking opportunities, other ways to get involved in long-term care advocacy and additional resources.

- [Family Council Information](#)
- [Family Council Rights and Federal Laws & Regulations](#)
- [Family Council Exchange](#)
- [Virginia Family Council Grants and Other Opportunities](#)
- [Learn and Take Action!](#)
- [Additional Resources](#)

What is the State LTC Ombudsman Program?



- Patty Ducayet, Texas State LTC Ombudsman
 - LTC Ombudsmen represent the interests of residents
 - Receive complaints from anyone on behalf of a resident

Advocating With an LTC Ombudsman

- Individual problems
 - Facility and corporate management
 - Coordinating with other agencies
- Systemic problems
 - Media
 - Lawmakers
 - State survey agency
 - National organizations

COMMON SITUATIONS:

WHAT YOU NEED TO KNOW!

Visitation

CMS Guidance, March 13, 2020

<https://www.cms.gov/files/document/qso-20-14-nh-revised.pdf>

- 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.
- Decisions about visitation during an end of life situation should be made on a case by case basis, ...

CMS Frequently Asked Questions, April 24, 2020

<https://www.cms.gov/files/document/qso-20-28-nh.pdf>

4. Q: The CMS memorandum (QSO-20-14-NH (Revised)) states that visitation should be allowed in “certain compassionate care situations, such as an end-of-life situation.” What is an example of a “compassionate care situation”?

A: The memorandum intends to provide general guidance on how to limit visitation as much as possible, while also acknowledging that there are times when visits should be allowed. We encourage frequent communication among patients, residents, families, facilities, and other health care providers when appropriate (e.g., hospice providers), so they can work together to identify when a visit for compassionate care is needed, and can be safely conducted. **One example of such a situation is one in which a resident is receiving hospice care and their health status is sharply declining, or when a resident is not enrolled in hospice, but their health status has sharply declined.**

Visitation: Advocacy Strategies

- Individually: Make the case that your loved one's situation fits the criteria for a compassionate care situation
- Family Council:
 - Urge the facility to expand its definition of a compassionate care situation
 - Try to work with administration to develop a plan for a phased-in approach to allowing visitation
- Individually and with Family Council:
 - Determine where your state is with developing reopening guidance
 - Provide input, help shape the guidance

Transfers/Discharges

Federal nursing home regulations provide protections:

- Advance written notice, generally 30 days prior to date of proposed transfer/discharge
- Right to appeal hearing in front of administrative law judge

Waiver of These Regulations in Only 3 Situations:

1. Resident with COVID-19 transferred to COVID-dedicated facility
2. Resident without COVID-19 transferred to Non-COVID facility
3. Transfer for 14-day observation

What Does This Mean?

“[W]e are only waiving the requirement ... for the written notice of transfer or discharge to be provided before the transfer or discharge. This notice must be provided as soon as practicable.”

- CMS, COVID-19 Emergency Declaration Blanket Waivers for Health Care Providers.

Residents Still Have Rights

Right to:

- Choice of where to be transferred/discharged
- Sufficient preparation and orientation to ensure a safe and orderly transfer

Transfers/Discharges: Advocacy Strategies

- Individually: Request the transfer be stopped for the moment; ask for a meeting to discuss options
- Individually and with Family Council: Advocate at both the facility and state level for:
 - Advance notice (at least 72 hours)
 - Advance conversation to explore options/make plans

LEAVING A FACILITY DURING COVID-19

- Going to a shared courtyard
- Going for a walk or out for lunch
- Going home with a family member for the duration

My mother wants to go outside to the courtyard!

If the facility has no active cases of COVID-19, there is no CMS guidance that says she can't!

FAQ QSO-20-28-NH <https://www.cms.gov/files/document/qso-20-28-nh.pdf>

Can a resident leave a nursing home for an appointment or outside activity?

“With regard to outside activities, the CMS memorandum (QSO-20-14-NH (Revised)) states that facilities should cancel “all group activities such as internal and external group activities.” This means there should be no group activities occurring outside or inside of the building, due to the risk of transmission.”

Yes, going outside on facility grounds should be permitted!

- There are facilities in some states that are starting to have “outdoor visitation.”
- There are facilities that are allowing smokers to go outside.
- As long as residents practice social distancing when outdoors they should be permitted to enjoy outdoor spaces.
- Outdoor recreation is encouraged during this time, it shouldn't be different for residents of long term care facilities.

What can you do?

- Talk to the facility
- Bring this up at a care planning meeting
- Get your ombudsman involved

My mother wants to go for a walk away from the facility or to lunch at a nearby restaurant. Can she?

QSO-20-28-NH <https://www.cms.gov/files/document/qso-20-28-nh.pdf>

What if a resident wants to leave the nursing home against medical advice?

“It is unlawful for a facility to detain and stop a resident from leaving the facility if the resident wishes to leave.... If a resident insists on leaving against medical advice, the facility must allow them to leave, should encourage them to wear a facemask while out in the community, discuss the importance of handwashing, offer hand sanitizer if available, and document in the resident’s medical record how the facility discouraged leaving and explained the risks of leaving to the resident and/or resident representative.

For a resident who leaves and intends to return, the facility should monitor the resident upon return for fever and signs and symptoms of respiratory infection for 14 days (preferably in a space dedicated for observation of asymptomatic residents), and implement the necessary Transmission-Based Precautions if the resident develops fever or signs and symptoms of respiratory infection.”

So what does this mean?

Your loved one CAN leave their facility!

BUT...

- They may be quarantined and monitored for 14 days upon return.
- They may be asked/required to take tests to determine their COVID-19 status.
- The facility may push back and not want to let them back in!

What can you do?

Discuss the decision with the facility **BEFORE** your loved one leaves.

Understand their policies.

Accept that monitoring and quarantine may be done for the safety of everyone within the facility. Once someone leaves the facility grounds, it's impossible to control where they go or whether they practice social distancing.

If you are uncomfortable with what the facility is requiring – contact your ombudsman!

Can I take my mother home for the duration of the pandemic?

Yes! But, there are many things to consider.

Does your loved one want to leave?

Residents have the right to leave the facility and reside somewhere else!

- Talk to the facility about whether your mother can return – and get it in writing!!!
- If her care is covered by Medicaid, what are your rights for holding her bed and her return in the future?

Is your home equipped for mother's needs? Consider:

- A special bed or other equipment – shower chair, wheelchair, elevated toilet seat
- Stairs and her ability to maneuver around the house
- Bathing, toileting, eating
- Lifting and Transferring in and out of bed or chairs – will a second person be needed?

Is someone available to provide 24/7 care if needed?

- If you need outside help, how will you pay for it?

Is there a risk of exposure to COVID-19

- Is everyone in your household practicing social distancing?
- What if someone gets infected while she's with you?

Who will oversee her medical care and medications?

- In the nursing home residents often rely on a medical director, will you be able to find a doctor in your community?

What if your mother becomes more ill in your home or needs more care than you can provide?

- Will you be able to bring in additional help?
- Will she need to return to a long-term care facility and if so, can she return to the facility where she currently lives?

See our checklist: http://eldermistreatment.usc.edu/wp-content/uploads/2020/06/CV_TakingAResidentHome.pdf

TRANSPARENCY DURING COVID-19

What does the facility have to report?

What should I be asking?

Where else can I find information?

What does the facility have to report?

FEDERAL REQUIREMENTS

Required to report to families, residents, and resident representatives: (by 5pm the next calendar day, following the occurrence of or weekly)

- Single confirmed infection OR
- Three or more residents or staff with new onset respiratory symptoms occurring within 72 hours of each other
- Actions they are taking to mitigate the spread of the virus

Required to report to CMS: (at least weekly)

- Suspected and confirmed COVID-19 cases among residents and staff
- Total deaths and total deaths from COVID-10
- Personal Protective Equipment and hand hygiene supplies
- Ventilator capacity and supplies
- Resident beds and census
- Access to testing in facility
- Staffing shortages

<https://www.govinfo.gov/content/pkg/FR-2020-05-08/pdf/2020-09608.pdf>

What does the facility have to report?

STATE REQUIREMENTS:

Many states have their own individual requirements

State COVID-19 Nursing Home Policies:

<https://theconsumervoice.org/state-information>

Information Current As of June 4, 2020

The information below reflects the state's current policy regarding the release of information to the public about Covid cases and deaths in nursing homes and assisted living facilities.

The federal government has required that all nursing homes report certain Covid-19 information to both the Centers for Disease Control and the Centers for Medicare & Medicaid Services (CMS). In addition, facilities must be reporting certain information to residents and their families. For information on what information must be reported to the federal government and to residents and their families, click [here](#). CMS plans to release the reported information to the public [here](#). The information below is what the state is doing separate from the federal reporting requirements.

Reporting Resident Cases	Yes
Reporting Resident Deaths	Yes
Reporting Staff Cases	Yes
Information Broken Down by Facility?	Yes
Reporting Cases in Assisted Living Facilities?	Yes

So what should I be asking?

- Make sure that the facility is giving you the information they are required to share!
- Ask them for more! Ask for regular updates!

There is no reason that families are not receiving public information.

- Individual advocacy
- Work with your family council

Where else can I find information?

Federal information:

CMS made State and facility level information available to the public in early June 2020.

<https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg>

State information:

State COVID-19 Nursing Home Policies:

<https://theconsumervoice.org/state-information>

Covid-19 Testing Hypothetical

- Mrs. Smith suffers from advanced dementia. She tends to become distressed when the facility performs invasive procedures, such as blood tests.
- The facility contacts her daughter, who is her designated representative, and tells her that the facility will be testing all residents for Covid-19 using a nasal swab.
- Daughter/representative is gravely concerned that her mother will not tolerate the intrusive procedure and it will cause her distress.
- Can daughter/representative refuse testing on Mrs. Smith's behalf?

Testing Continued

- Mrs. Smith has a right to designate a representative who can exercise her rights. 42 C.F.R. § 483.10(b)(3).
- The facility must treat the decisions of the representative as the decision of Mrs. Smith. 42 C.F.R. § 483.10(b)(4).
- Mrs. Smith, and therefore, her representative, has the right to refuse treatment. 42 C.F.R. § 483.10(c)(6).

Testing Continued

- Request alternative form of testing.
- Could be quarantined for 14 days.
- Could be threatened by facility with discharge.
 - Contact local ombudsman
 - Contact state licensing agency

Join With Others

- State advocacy groups
 - Citizen advocacy groups https://theconsumervoice.org/get_help
 - AARP state chapters
 - Other groups?
- Long-Term Care Ombudsman Program
https://theconsumervoice.org/get_help
- Consumer Voice
 - Join Action Network <https://act.theconsumervoice.org/join-action-network>

RESOURCES

Consumer Voice: COVID-19 in Long-term Care Facilities:

<https://theconsumervoice.org/issues/other-issues-and-resources/covid-19>

Keeping Families Together Checklist:

http://eldermistreatment.usc.edu/wp-content/uploads/2020/06/NCEA_KeepingFamillysTogether.pdf

Should I Take My Loved One Home During the COVID-19 Crisis:

http://eldermistreatment.usc.edu/wp-content/uploads/2020/06/CV_TakingAResidentHome.pdf

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