



The National

CONSUMER VOICE

for Quality Long-Term Care

formerly NCCNHR

PUT A **STOP** TO POOR CARE: ADVOCATING FOR QUALITY CARE



Wednesday, November 18, 2015

Agenda

- **Julie Schoen, Deputy Director, National Center on Elder Abuse (NCEA)**
 - NCEA
- **Robyn Grant, Director, Public Policy and Advocacy, CV**
 - What is quality care?
- **Kathy Bradley, CEO and Board President of Our Mother's Voice**
 - What can you do?
- **Amity Overall-Laib, Acting Director, National Long-Term Care Ombudsman Resource Center (NORC)**
 - What is a Long-Term Care Ombudsman?

The Consumer Voice

- The National Consumer Voice for Quality Long-Term Care (Consumer Voice) is a national, non-profit organization in Washington, D.C. that advocates for people receiving care and services at home, in assisted living, or in a nursing home.
- Clearinghouse of information and resources for empowering consumers, families, caregivers, advocates and ombudsmen in seeking quality care, no matter where.
- Provide technical assistance and support for state advocacy regarding long-term care services and supports and have a national action network.

THE NATIONAL CENTER ON ELDER ABUSE

Funded by a grant from the Administration on Community Living and Administration on Aging (ACL/AoA), serving as one of 27 National Resource Centers. The NCEA is a provider of up-to-date, pertinent and valuable resources, education, and information on elder abuse and neglect.

As a leader in the elder justice movement, we:

- Create valuable educational resources
- Provide training curricula tailored to a variety of audiences
- Deliver up-to-date research
- Build partnerships and make connections
- Explore innovative models
- Listen to what the field needs
- Take advantage of opportunities to advance the field
- Communicate our efforts
- Envision our goals for tomorrow



THE NATIONAL CENTER ON ELDER ABUSE

The NCEA disseminates information and provides technical assistance and training to professionals and the lay public by:

- Making news and resources available
- Collaborating on and disseminating research
- Distribution of monthly themed blogs
- Identifying information about promising practices and interventions
- Operating a professional and student listserv
- Providing subject matter expertise



What is Quality Care?

- **Quality Care**

- Is individualized to meet the care needs and preferences of **each resident**.
- Promotes resident **dignity, choice, and self-determination** in all aspects of life and care.
- Improves, or maintains, the **highest practicable well-being** of each resident.

Rights, Law, and Regulations

- **All residents**, regardless of the type of facility, have:
 - the same rights as those in the larger community plus additional protection in federal and/or state law and regulation.
 - the right to be protected from mistreatment, including abuse, neglect, and exploitation and are entitled quality, individualized care.
- There are federal requirements for participation in Medicare and Medicaid for nursing homes, but no federal regulations for assisted living.

Signs of Quality Care



- Quick and kind response to call lights.
 - Resident involvement in care and daily life is encouraged.
 - Residents appear clean, well groomed, comfortable, engaged, happy, and without visible restraints.
 - Residents' rights are respected and supported.
- Facility is clean, clutter and odor free, comfortable temperature.
 - Food is appetizing.
 - Community is warm and engaging.
 - Staff know residents and communicate respectfully.
 - Meaningful individual and group activities.

Advocacy Tips



- Get to know other residents, especially those without family or visitors.
- Get involved in the Resident or Family Council.
- Share information about residents' rights and signs of quality care.
- Communicate with staff, compliment good care.
- Learn about the Long-Term Care Ombudsman (LTCO) Program and get to know your local ombudsman.
- If you are a family member or friend, continue to visit often and at varying times.

Warning Signs



- Facility appears understaffed (e.g. call lights not answered promptly).
- Residents' rights are not respected (e.g. no choices in daily routine, not involved in care decisions).
- Quality and quantity of food declines.
- High staff turnover, staff not familiar with residents.

- Residents appear bored, less active, not engaged with others or activities.
- Residents and/or family members say concerns have not been resolved.
- Facility uncomfortable (e.g. not clean, has an odor, too cold/hot, too noisy).
- Medication errors.

Advocacy Tips



- Work with the Resident or Family Council to address concerns as a group.
- Become familiar with residents' rights and facility requirements (federal and/or state).
- Document your concerns. Discuss your concerns with the Administrator or other key staff, share your observations, and resolution goal.
- Contact the Long-Term Care Ombudsman Program.
- Visit frequently, vary the time of your visits, and take notes of any issues you identify.
- Review state survey reports to see if the facility has been cited for similar issues before.

Red Flags



- Significant, sudden change in behavior (e.g. withdrawn, fearful, lack of appetite).
- Dramatic physical changes (e.g. weight loss, decline in mobility).
- Unexplained injuries (e.g. bruising).
- Residents are physically restrained and/or appear to be over medicated (e.g. slumped in wheelchairs).

- Severe lack of staff (e.g. no response to call lights, frequent falls, lack of assistance to use the restroom).
- Residents appear unclean, have body odors.
- Staff disregard residents and their rights. Complaints are ignored.
- Missing personal items or funds.

Advocacy Tips



- Take detailed notes of concerns (names, dates, times of incidents).
- Contact the facility owner and/or corporate office and share your concerns.
- Contact the Ombudsman if complaints are not resolved, staff is unresponsive, and/or for information or advocacy.
- Contact the state survey agency to file complaints, be as specific as possible.
- Report any suspected abuse, neglect, or exploitation to the investigating agency (e.g. state survey agency or Adult Protective Services) and/or local law enforcement.

Address Concerns:

Clearly, Directly, and Promptly

- **Before speaking with the staff, define the issue.**
 - Stick to the facts, your observations, and resident direction regarding care needs and preferences.
- **Focus on the problem, not the person, and avoid using emotive words that are tied to a person's perception.**
- **Be direct, specific, and non-judgmental.**
 - Describe the situation without sharing your opinion about why it happened.
- **Discuss your resolution goal, document everything, follow-up with the staff if the issue is not fully resolved.**

Address Concerns:

Clearly, Directly, and Promptly

Avoid Saying...	Say this instead...
“Why are the aides so late in responding to my call light after dinner?”	“I need assistance getting to the restroom after dinner and for the last 3 nights I’ve had to wait for at least 20 minutes. How will this be addressed so I get the help I need?”
“When you...”	“What I would like to see happen is...”
“The evening aid <i>barged</i> into the room”	“She came into the room suddenly while my Mother was sleeping.”
“You are understaffed on the weekend.”	“During the week my mother’s call bell is answered promptly, but the last two weekends she has waited for up to 20 minutes for a response.”

WHAT CAN YOU DO?

Kathy Bradley

WHAT YOU CAN DO:



"The Sentry Box" by Carol J Hay

Families can learn about their loved one, the nursing home, and the regulations, to equip themselves to be advocates for services that will provide the best practicable quality of life for their loved ones in nursing homes.

Families are the safeguards for their loved ones who cannot protect themselves.

WHAT YOU CAN DO:

1. Stay involved with your family member after s/he is placed in the nursing facility. Visit. Learn the plan of care, and make sure it meets your loved one's needs. Provide information to staff that will help the plan of care to be complete and meaningful. Communicate regularly with your family member's social worker.
2. Observe your surroundings when you visit the facility: your loved one, other residents, the building, the staff. Note anything good, and let the staff know. Note anything that doesn't seem right. Look for "trends" – more than one occurrence of that thing.
3. Ask questions of the staff, and work with them if you see anything that needs attention, even if it is not a trend. If not addressed, it could become one.
4. Become familiar with the facility policies and state regulations that apply so that you know what should be happening. Identify specific problems or violations that exist and talk with management staff.
5. Approach the facility administration, and then the corporate leadership if those violations or problems persist. Cite the policies and regulations that are in violation, and give examples of your observations and efforts to work with staff to correct them. Make notes for yourself so that you will be thorough and accurate when you approach these officials.

6. If these efforts fail, the state regulatory agency has a complaint reporting process. They will need the information you have in writing (you should already have it from following steps 1-5 above), and they will refer you to the agency staff who takes reports of complaints or violations.
7. The regulating agency will determine whether investigation is warranted. Follow up with the regulatory agency after they have completed an investigation, to learn what they found and what to expect the facility to do in response to the investigation.

Ideally, you should not have to go beyond step 4. If you know what should be happening, understand the policies and regulations, and work with staff, you should be able to resolve most issues. We have included steps 5 – 7 because there are a small number of cases in which they may be needed.

8. Many facilities have Family Councils, organized to provide families with a voice and a venue to discuss, learn, and interact with the facility administration on behalf of all residents and their families. Often these Councils also occasionally conduct special activities for residents. You may want to become involved with the Family Council if your loved one's facility has such a group. If not, you may want to advocate for the establishment of a Family Council.



The National **Long-Term Care** **Ombudsman** Resource Center

WHAT IS A LONG-TERM CARE OMBUDSMAN?

Amity Overall-Laib

Acting Director, NORC

What is a Long-Term Care Ombudsman?

- A Long-Term Care Ombudsman (LTCO) is a resident advocate.
- LTCO advocate for quality of care and quality of life of residents in long-term care (nursing homes, board and care/assisted living, other similar adult care facilities).
- LTCO provisions in the Older Americans Act (OAA) include:
 - Investigate and resolve complaints
 - Provide information to residents, families, staff (e.g. residents' rights)
 - Advocate for systemic changes to improve residents' care and quality of life.

LTCOP Responsibilities

- Identify, investigate and resolve complaints made by or on behalf of residents.
- Provide information to residents about long-term care services.
- Provide technical support for the development of resident and family councils.
- Advocate for changes to improve residents' quality of life and care.
- Represent resident interests before governmental agencies.
- Seek legal, administrative, and other remedies to protect residents.
- Ensure residents have regular and timely access to the LTCOP.



Role of the LTCOP: Long-Term Care Ombudsmen...

<u>Do not</u> conduct licensing and regulatory inspections or investigations	<ul style="list-style-type: none">• LTCO are knowledgeable of federal and state regulations and will refer to relevant regulations as they advocate for the highest quality of care and life for residents.• If necessary, with resident consent, LTCO will file a complaint with licensing and regulatory.
<u>Are not</u> Adult Protective Services (APS) investigators	<ul style="list-style-type: none">• LTCO provide information regarding preventing and reporting abuse, neglect, and exploitation.• LTCOPs do not have the same standard of evidence requirement as APS and are not the “official finder of fact.” LTCOPs attempt to resolve complaints to the residents’ satisfaction, not gather evidence to substantiate that abuse occurred.• If necessary, with resident consent or permission of the State LTCO if the resident can’t consent and does not have a legal representative, the LTCO will file a complaint about alleged abuse.
<u>Do not</u> provide direct care for residents	<ul style="list-style-type: none">• LTCO share information about quality care practices and ways to enhance the quality of life for residents.• LTCO are a resource for staff training and provide information for community resources.

State LTCO Programs

- **LTCO visit residents in:**
 - Nursing homes and assisted living facilities/board and care homes.
 - In a small number of states, LTCOPs also visit individuals that receive long-term care services in their own home.
- **Do LTCO represent all residents, regardless of age?**
 - OAA programs provide services to individuals 60 and older, but the LTCOP will assist residents younger than 60 as advocacy for individuals younger than 60 will also benefit other residents.
- **How often do LTCO visit?**
 - LTCO regularly visit facilities in order to provide access to the program, but how often depends on the program (e.g. weekly, monthly, quarterly).

LTCO Complaint Investigation

- LTCO investigate individual complaints and address concerns that impact several or all residents in a facility.
- LTCO can address general concerns they personally observe during a visit (e.g. odors, environmental issues).
- During complaint investigations LTCO cannot share information without resident consent. Some residents ask to remain anonymous.
- Investigate to gather the facts, but the main goal is to resolve the issue to the residents' satisfaction.
- LTCO call upon others to fulfill their responsibilities to residents.

LTCO Complaint Investigation

- If the complaint is from someone other than the resident, the LTCO will visit the resident in order to understand the resident's capacity to make decisions.
 - If the resident cannot provide consent, the LTCO will work with the resident's legal representative or follow their state procedure if the resident doesn't have a legal representative.
- Federal law grants LTCO access to resident information (with resident permission) and LTCO are required to keep that information confidential.
- In accordance with federal law, facilities must provide the LTCOP with immediate access to residents.

Type of Complaints

- LTCO handle a variety of complaints about quality of life and care.
- Not all complaints are about the care provided by a facility, some complaints are about outside agencies, services or individuals (e.g. Medicaid or Medicare benefits).
- LTCO can receive and respond to complaints from individuals other than the resident (e.g. family member), but LTCO still need resident permission to investigate or share information.
- Nationwide, in 2014 the LTCOP investigated 191,533 complaints in nursing homes and board and care facilities.

How to Contact the LTCOP

- Nursing homes are required to post contact information for the LTCOP and some states require assisted living facilities/board and care facilities to post information about the LTCOP.
- Visit the National Long-Term Care Ombudsman Resource Center website to locate your local or state LTCO:
<http://www.ltcombudsman.org/>

Locate an Ombudsman

Find an Ombudsman, Citizen Advocacy Group (CAG), or other long-term care resources in your state or territory. Citizen Advocacy Groups are concerned citizens who advocate for quality long-term care, services and supports and quality of life for residents and consumers in their locality, state or region.

[Learn more about ombudsmen →](#)



QUESTIONS?

RESOURCES

Put a STOP to Poor Care

<http://theconsumervoice.org/news/detail/latest/cv-and-ncea-produce-put-a-stop-to-poor-care-brochure>

Front



All long-term care residents have the right:

- To receive quality, individualized care
- To be protected from mistreatment, including abuse, neglect, and exploitation.

Quality care promotes resident dignity, choice, and self-determination in all aspects of life and care.

Individuals living in nursing homes and assisted living facilities **maintain the same rights as individuals in the larger community** and have additional rights and protections in federal and state law.

Nursing homes must meet federal requirements if they participate in Medicare and Medicaid. There are no federal regulations for assisted living facilities so requirements are different in each state.¹



¹ Fact sheets and information regarding residents' rights, abuse, and advocating for quality care are available on the Consumer Voice website www.theconsumervoice.org.

Inside

SIGNS OF QUALITY CARE	WARNING SIGNS	RED FLAGS
<ul style="list-style-type: none"> • Facility is clean, clutter free, smells fresh, and not too hot or cold. • Calls for assistance (e.g. call lights) are responded to quickly and kindly. • Residents appear well groomed, clean, comfortable, alert, happy, and are without visible restraints. • Food looks and smells appetizing. • Staff encourage resident involvement in their care and daily life (e.g. residents choose when to wake up). • Residents are involved in meaningful activities (both individual and group). • Community is warm and engaging (e.g. staff know residents and communicate respectfully). 	<ul style="list-style-type: none"> • Facility appears understaffed (e.g. call lights not answered promptly or turned off without care being provided). • Residents' rights are not respected (e.g. no choices in daily routine, not involved in care decisions). • Quality of food declines (e.g. fewer meal options, less food served, menu not followed). • High staff turnover, staff not familiar with residents. • Residents appear bored, less active, not engaged with others or activities. • Residents and/or family members say concerns have not been resolved. • Facility uncomfortable (e.g. not clean, has an odor, too cold/hot, too noisy). • Medication errors. 	<ul style="list-style-type: none"> • Significant, sudden change in behavior (e.g. withdrawn, fearful, lack of appetite). • Dramatic physical changes (e.g. weight loss, decline in mobility). • Unexplained injuries (e.g. bruising). • Residents are physically restrained and/or appear to be over medicated (e.g. slumped in wheelchairs). • Severe lack of staff (e.g. no response to call lights, frequent falls, lack of assistance to use the restroom). • Residents appear unclean, have body odors. • Staff disregard residents and their rights. Complaints are ignored. • Missing personal items or funds.
ADVOCACY TIPS	ADVOCACY TIPS	ADVOCACY TIPS
<ul style="list-style-type: none"> • Get involved in the Resident or Family Council. • Get to know other residents, especially those without family or visitors. • Share information about residents' rights and signs of quality care. • Communicate with staff, compliment good care. • Learn about the Long-Term Care Ombudsman (LTCO) Program and get to know your local ombudsman. • If you are a family member or friend, continue to visit often and at varying times. 	<ul style="list-style-type: none"> • Work with the Resident or Family Council to address concerns as a group. • Become familiar with residents' rights and facility requirements (federal and/or state). • Document your concerns. • Discuss your concerns with the Administrator, share your observations, and resolution goal. • Share your concerns with the LTCO. • Visit frequently, vary the time of your visits, and take notes of any issues you identify. • Review state survey reports to see if the facility has been cited for similar issues before. 	<ul style="list-style-type: none"> • Take detailed notes of concerns (names, dates, times of incidents). • Contact the facility owner and/or corporate office and share your concerns. • Contact the Ombudsman if complaints are not resolved, staff is unresponsive, and/or for information or advocacy. • Contact the state survey agency to file complaints, be as specific as possible. • Report any suspected abuse, neglect, or exploitation to investigating agency and/or local law enforcement.

ADVOCATE FOR QUALITY CARE!

This resource highlights indicators of care to help you identify quality care and provides steps to address any areas of concern.

RESIDENTS: Share this with your peers, both individually and in Resident Council meetings, talk about what quality care means to you, and how to advocate for your needs.

FAMILY MEMBERS: Use this resource to inform your observations during visits with your loved one and to advocate for quality care.

All residents have the right to quality care and to be free from mistreatment. There are agencies responsible for investigating complaints, including those regarding resident abuse, neglect, and exploitation.

QUALITY CARE

- Is individualized to meet the care needs and preferences of each resident.
- Improves, or maintains, the highest practicable well-being of each resident.
- Promotes resident dignity, choice, and self-determination in all aspects of life and care.



Specialized Information for:

[Long-Term Care Consumers](#) [Family Members](#) [Advocates](#)

Consumer Voice to Offer FREE Advocacy Skills Training Webinars



As part of our Consumers for Quality Care, No Matter Where initiative, Consumer Voice will be conducting four FREE advocacy skills training webinars throughout the year.

[More Information](#)



Consumer Voice Clearinghouse ▶ **Your one-stop destination for long-term care information**

www.theconsumervoice.org

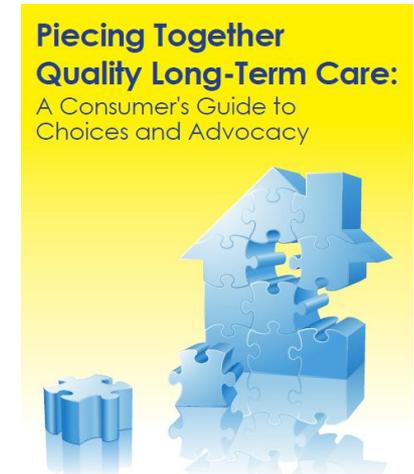
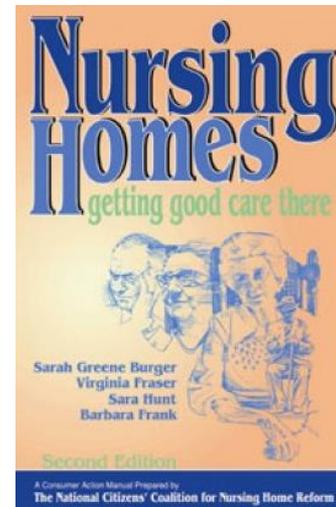
- **Fact Sheets**

- Assessment and Care Planning
- Basics of Individualized Care
- Residents' Rights
- Guide to Choosing a Nursing Home
- Abuse and Neglect
- Emergency Preparedness
- Restraint Free Care

- **Resident and Family Council information**

- **Guides**

- Piecing Together Quality Long-Term Care: A Consumer's Guide to Choices and Advocacy
- Nursing Homes: Getting Good Care There



The National Center on Elder Abuse

The goal of the NCEA is to improve the national response to elder abuse, neglect, and exploitation by gathering, housing, disseminating, and stimulating innovative, validated methods of practice, education, research and policy.

Find the NCEA Online!



ncea.aoa.gov



gero.usc.edu/cda_blog/



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