# COMING TOGETHER TO CREATE CHANGE: A SYMPOSIUM FOR THE NURSING HOME COMMUNITY

Presented by Richard Mollot, Long Term Care Community Coalition

www.nursinghome411.org

This program was made possible by the generous support of the NYS Health Foundation.

# What Will We Be Talking About TODAY?



- **Brief Recap of…**
  - The Federal Nursing Home Law and
  - Residents' Rights
- **Highlights of the Presentation on Dementia Care by Dr. Jonathan Evans**
- **Highlights of the Presentation on Transfer & Discharge by Lindsay Heckler**
- **Useful Tools & Resources**
  - Handy Reference Materials
  - Useful Forms for Record-Keeping, Tracking, and Speaking Out About Concerns

# The Nursing Home Reform Law

- The Nursing Home Reform Law (aka OBRA 87) requires that **every nursing home resident** is provided the care and quality of life services sufficient to attain and maintain his or her **highest practicable** physical, emotional, and psycho-social **well-being**.


- This is what we pay for.
- This is what providers agree to provide.
- This is what every resident deserves.

# The Nursing Home Reform Law

- Emphasis on **individualized, resident-centered care** – to reduce problems, including abuse and neglect, and ensure that residents are treated with dignity and have a good quality of life.
- The law lays out specific **resident rights**, from good care and monitoring to a quality of life that maximizes choice, dignity and autonomy.

# Persistent Problems

**Unfortunately, too many residents are subjected to neglect, substandard care, abuse…**

- The majority of nursing homes have less staffing than federal studies have indicated as necessary to meet residents' basic needs.
- Antipsychotic drugging, a major problem, continues to be pervasive.
- Unwanted discharges from nursing homes are a top complaint from residents and families.
- 2014 federal study found that 1/3 of short-term, rehab residents are harmed within about two weeks of entering the nursing home. 59% of that harm was avoidable.

## Persistent Problems – Why?

While many facilities provide good care and life with dignity for their residents, in the absence of vigorous enforcement of minimum care standards, too many facilities will skimp on staffing and services to increase profits.

## So, What Can WE Do?

1. **Know residents' rights**. We cannot advocate for our rights if we don't know what they are.
2. **Be equipped for advocacy**. Having good supports – people, information, tools – is essential for effective advocacy.

# Dementia Care:
# Highlights from the Presentation by Dr. Jonathan Evans

# What's the Problem?

- Millions of Americans with Alzheimer's disease and other forms of dementia 'misbehave' in ways that are bothersome to caregivers and others (wandering, yelling, 'agitation', etc)
- **For 70+ years, doctors and nurses have *been taught to use tranquilizers* in these instances to try to make patients behave** (conform to the rules/norms/ routines of the environment)
- Health care environments are inflexible, confusing, and often scary to most patients even without Alzheimer's disease.
- People with dementia have limited ability to reason/comprehend the world around them-
  - They often perceive the behavior of others as threatening and respond reflexively or inadvertently break rules like opening doors, entering places like other's rooms that are 'off limits', etc
  - **Doctors and nurses have not been taught what to do instead of using tranquilizers.**
- ***'If all you have is a hammer, everything looks like a nail'***

# What's The Problem?

- Drugs administered to Make People Behave Don't Make People behave Better
- They are way more dangerous than prescribers and others think
- The use of these medicines in patients with dementia is a symptom of other problems within healthcare: cultural, attitudinal, educational structural  i.e. staffing, lack of supervision of patients, physical environmental hazards)
  - Mostly represents caregiver frustration, stress
  - Doing something over and over again that is harmful, very expensive,  and ineffective indicates much broader failures  in American Healthcare

# Drugs Used to Try To Make People Behave

- Antipsychotic drugs ineffective in making people with dementia behave
  - CATIE-AD Trial NEJM (2006), BMJ Seroquel trial
  - **In studies, staff believed the medicines were working when they weren't**
- **These medicines don't work to treat behavior in people with Dementia**
  - **Even as a last resort- they still don't work and they are harmful**
  - **Their use often represents caregiver frustration, stress, a desire to make the problem 'go away'**
  - **It's like hitting the TV on the side, hoping to make the picture better**

# Antipsychotic and Other Psychotropic Drugs In Dementia

- These drugs are harmful and the don’t do what we wish they would do
- Increased death from antipsychotics, anticonvulsants, benzodiazepines in patients with dementia
- *It is estimated that the number of Americans with dementia  who die as a result fo being prescribed these drugs is higher than the number of Americans overall who die each year from being prescribed opioids.*

# Antipsychotic And Other Psychotropic Drugs in Dementia

- Various Studies: No correlation between patient symptoms/severity and use of antipsychotics in nursing homes
- Strong correlation between which facility admitted to and likelihood of receiving antipsychotic drug
- Use of antipsychotics in dementia correlates most closely with ‘facility culture’
- National efforts to reduce antipsychotic drugs in patients with dementia have resulted in switching to other sedating drugs instead
- (Maust JAMA Internal Medicine 2018)

"Doctor,

what can

you do

for Pop?"

for prompt control of

# senile agitation

## THORAZINE*

(chlorpromazine, S.K.F.)

'Thorazine' can control the agitated, belligerent senile and help the patient to live a composed and useful life.

Smith Kline & French Laboratories

to help you relieve

the severe emotional upset

of the menopausal patient

# THORAZINE*

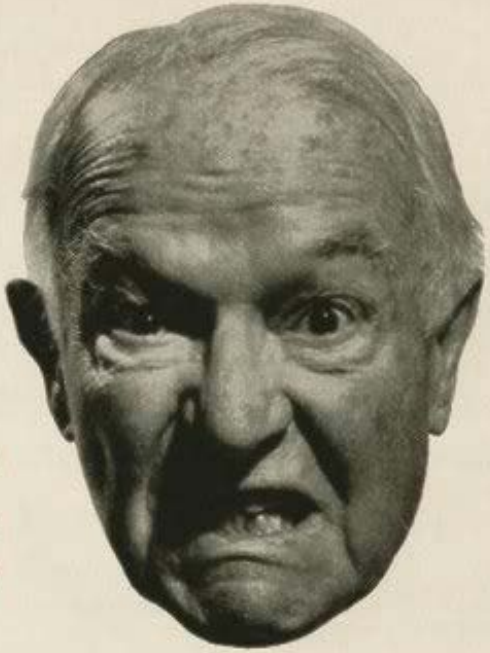
'Thorazine' can facilitate the over-all management of your menopausal patient. Its unique, non-hypnotic tranquilizing effect relieves anxiety, tension, agitated depression and helps you to restore to the patient a feeling of well-being and a sense of belonging.

'Thorazine' is available in ampuls, tablets and syrup (as the hydrochloride), and in suppositories (as the base).

*For information write:*

Smith, Kline & French Laboratories, Philadelphia 1

*T.M. Reg. U.S. Pat. Off. for chlorpromazine, S.K.F.



*Tyrant in the house?*

'Thorazine' can control the agitated, belligerent senile

and help the patient to live a composed and useful life.

When 'Thorazine' is administered to the agitated senile, there is a marked decrease in his nerve-racking outbursts of hostility, irritability, abusiveness, incessant talking and "day-and-night" pacing or restlessness.

On 'Thorazine' therapy, the patient often forms more regular eating and sleeping habits and improves in his personal hygiene. As the patient becomes more tractable and cooperative, he is able to live a composed and useful life.

THORAZINE*

chlorpromazine, S.K.F.

*one of the fundamental drugs in medicine*

*Smith Kline & French Laboratories, Philadelphia*

*T.M. Reg. U.S. Pat. Off.

# Use of Antipsychotic Drugs Determined By Facility Culture

- **Unexplained Variation Across US Nursing Homes in Antipsychotic Prescribing Rates**
  - **Chen et al. Arch Int Med Jan 11, 2010**
- **Variation in Nursing Home Antipsychotic Prescribing Rates**
  - **Rochon et al. Arch Int Med April 2007**

# Antipsychotic therapy and short-term serious events in older adults with dementia. Rochon PA et al, Annals of Internal Medicine May 2008.

- Retrospective cohort study
- A large study over 7 years involving almost 21,000 community dwelling subjects with dementia
- Subjects newly prescribed antipsychotic drugs 3.2 to 3.8 times more likely to develop serious adverse events within 30 days
  - 3.2 times for atypical antipsychotics
  - 3.8 times for typical antipsychotics
- Serious events are frequent following short term use of antipsychotic drugs

# July 2012 OIG Report

- 99% of facilities nationwide deficient in assessment, developing, implementing comprehensive care plan when antipsychotic drugs used for behavior in dementia
- Antipsychotic drugs used *instead of* proper nursing care

- Bottom line: antipsychotic prescribing to control behavior a ‘red flag’ that invites regulatory scrutiny
- Antipsychotic drug use = care plan deficiency citation for facility

# Antipsychotic and Other Drug Use in Dementia

- These drugs are dangerous
- They don't do what we wished they would do
- They are overused now
- Their use is actively discouraged by FDA, others
- Their use creates unrealistic expectations, distracts care providers from solving the underlying problems associated with undesirable behavior
- 75% or more of patients with dementia prescribed these medications do not live in nursing homes!

# Behavior Case 1

- Male patient, resident of home for 18 months
- Requires ‘total care’
- Frequent agitation, yelling, crying, wandering
- Unable to communicate needs verbally
- Often ‘resists care’
- Frequently bites, scratches caregivers
- Destroys other residents’ property


Wheel Horse

- **Behavior is Communication**

- ***Behavior is not a disease!***

# Behavior Case 2

- **You leave here in a hurry to pick up your child (or grandchild) from daycare this evening**
- **When you arrive, you are told by the director that your 3 year old beloved had a rough morning but he was given a medication that helped a lot. He is sleeping deeply now, with snoring respirations, falls back to sleep immediately when you try to wake him, and he has been incontinent of urine despite being successfully potty trained over a year ago.**
- **How do *you* feel?**

# Behavior is Communication

- Most ‘challenging’ behaviors in institutional settings are *reactive*
  - often caused by and/or exacerbated by *misunderstanding/misperception on the part of either patients or staff*
- Patients with confusion have altered perception by definition
- Patients with dementia lose the ability to comprehend, understand, reason
- Attempting to reason with someone who has lost the ability to reason is unreasonable

# Behavior is Communication

- **"Challenging" behaviors Most often represent a *conflict between the individual and their environment***
- ***especially the human environment***

**Primary Task: Figure out *meaning***

*. . . . Why do they do that?*

*. . . . What are they trying to say?*

***Interpret behavior in the context of one's life experience***

# Behavior is Communication

- ***Are they telling you that they are in distress?***
  - **or are they causing distress to others?**
- **The approach to prevention and management is quite different, depending upon the answer to this question**
- **For patients in distress, look for and modify/eliminate/treat the underlying cause (what or whom)**

# General approach

- What are they trying to say?
- What are they reacting to?
- Look for meaning
- Determine if patient is in distress and if so evaluate cause
- Most often situational
- Behavior history to identify precipitants/antecedents, help interpret meaning
  - Get information from nursing assistants, families, nonmedical staff, multiple nurses (different shifts)

# Taking a behavior history

- Team approach to behavior interpretation, response
- Precise evaluation of behaviors, circumstances, triggers
- What happened, when. Who was there? What were *they* doing? What was the patient doing before the behavior occurred?
- Context- an understanding of patient and their life, relationships, prior to dementia onset very helpful in understanding behavior and providing care
- CNAs those with the most patient contact and least power often most effective

# Behavior History cont'd

- Consider that behavior may be a medical symptom of something other than dementia
- Behavior history similar to eval of pain- onset, duration, precipitating events, aggravating factors, alleviating factors, associated symptoms,etc. except that patient can't provide any history themselves
- Behavior log for facility staff

# Behavior as Communication

- Labeling of behaviors (and patients) as "bad" or "difficult" may create a set of expectations and foster a sense of futility or resignation
  - becomes self-fulfilling

- People with dementia often comprehend/respond to nonverbal communication (behavior) better than words

- *Mirroring* the affect of others (residents, caregivers)

+

# Involuntary Transfer/Discharge:

Presented by Lindsay Heckler

CENTER FOR ELDER LAW & JUSTICE

# 6 Allowable Reasons for Involuntary Discharge/Transfer

1. Necessary for the resident's welfare and resident's needs cannot be met at the facility;
2. Resident's health has improved sufficiently so resident no longer needs nursing home level of care;
3. Safety of individuals in the facility is endangered due to the clinical or behavioral status of the resident;
4. Health of individuals in the facility would otherwise be endangered;
5. Resident has failed, after reasonable and appropriate notice, to pay for (or to have paid under Medicare or Medicaid) a stay at the facility*; or
6. Facility closes.

CENTER FOR ELDER LAW & JUSTICE

# Other Requirement: Written Notice

Timing of Notice

- General rule is 30 days
- "As soon as practicable" but no later than the date on which the determination was made

Content of Notice

- Reason for discharge;
- Specific regulations that support the discharge or change in law that requires it;
- Effective date for the discharge;
- Location to where the resident is being discharged;
- Statement the resident has the right to appeal to New York State Department of Health; and
- Name, address, and phone number of the State Long Term Care Ombudsman Program

CENTER FOR ELDER LAW & JUSTICE

# Other Requirement: Safe Discharge

Discharge location must be safe

- Questionable discharges:
  - Hotel
  - Shelter
  - DSS
- Home of relative or friend
  - Does the relative/friend want the resident in his/her home?
  - Is the home safe for the resident?

Facility must engage in proper discharge planning!

CENTER FOR ELDER LAW & JUSTICE

# Appealing Nursing Home Discharge In New York State

Step 1: Call New York State Department of Health (NYS DOH) and state you are appealing the discharge. (Be specific it is the same # as the complaint hotline!)

- 1-888-201-4563

Step 2: NYS DOH will request a copy of the notice from the facility to review it for validity 'on its face'.

- If notice is invalid, facility will be informed it cannot discharge resident
  - i.e. Discharge location is "TBD"
- If valid→ Step 3

Step 3: NYS DOH Bureau of Adjudication

- Sets the date/time/place of the hearing before an Administrative Law Judge (ALJ)
- Hearing will typically be where the resident is located.

CENTER FOR ELDER LAW & JUSTICE

# Issue: "Patient Dumping" at Hospitals

*When nursing home transfers the resident to a hospital and refuses to readmit them to the first available bed.*

Reasons why facility would do this?

- Resident (or family) is labeled as 'difficult'
- Resident has 'behaviors' that the facility chooses not to properly treat/provide care for

Reason used by facility for discharge:

- Necessary for resident's welfare and resident's needs cannot be met
- Safety/Health of individuals in facility is endangered

Things to remember:

- It is extremely rare that a discharge to a hospital is appropriate!
- Decision to discharge a resident should not be made based on the time of transfer to the hospital!
- Discharge notice must be issued to the resident (and designated representative)!

CENTER FOR ELDER LAW & JUSTICE

# Advocacy Tips

For Ombudsman Programs

- Track calls/complaints and look for patterns.
- Reach out to Hospital Discharge Planner and explain resident right to return to the facility and appeal rights.

For Residents and Family/Supporters

- Assess: do I want to return to the nursing home? Are there other nursing homes that could provide better care and quality of life?
- If no: appeal the discharge notice to Department of Health
  - Nursing home, under pressure, may agree to accept resident prior to ALJ hearing.
  - Nursing home has to prove it conducted proper discharge planning.

CENTER FOR ELDER LAW & JUSTICE

# Issue: Nursing Home ⟺ Nursing Home Transfer

- Common legal reasons for discharge that are used:
  - Resident's welfare and resident's needs cannot be met at the facility.
  - Resident's health has improved sufficiently so the resident no longer needs the services provided by the facility.
- Transfer for Long Term Care "LTC" is not one of the 6 legal reasons a facility can move a resident to another facility.
  - Nursing homes cannot discriminate on basis of payer source.
  - Every nursing home in NYS is dually Medicare & Medicaid certified.
    - This means if a resident exhausts his/her Medicare coverage of the nursing home stay and is now classified as someone who needs "LTC" or "custodial" care, the facility cannot claim they do not have any beds available for "LTC" and transfer the resident.

Tips for ombudsmen and residents/family/supporters:

- If a resident is being transferred to another nursing home, ask why.
- It is likely the transfer is inappropriate and resident is encouraged to appeal the transfer.

CENTER FOR ELDER LAW & JUSTICE

# Issue: Discharge for Failure to Pay

10 NYCRR 415(h)(1)(i)(b)

- Transfer and discharge shall also be permissible when the resident has failed, after reasonable and appropriate notice, to pay for (or to have paid under Medicare, Medicaid or third-party insurance) a stay at the facility.
- For a resident who becomes eligible for Medicaid after admission to a facility, the facility may charge a resident only allowable charges under Medicaid.
- Such transfer or discharge shall be permissible only if a charge is not in dispute, no appeal of a denial of benefits is pending, or **funds for payment are actually available and the resident refuses to cooperate with the facility in obtaining the funds**.

CENTER FOR ELDER LAW & JUSTICE

# Advocacy Tips

Is there a safe discharge location?

Prior to appeal/hearing - be proactive- ask questions!

- Why is the resident's stay not being covered?
  - Financial exploitation by POA, family/friend?
  - Insurance coverage denial?
  - Resident refusing to cooperate?

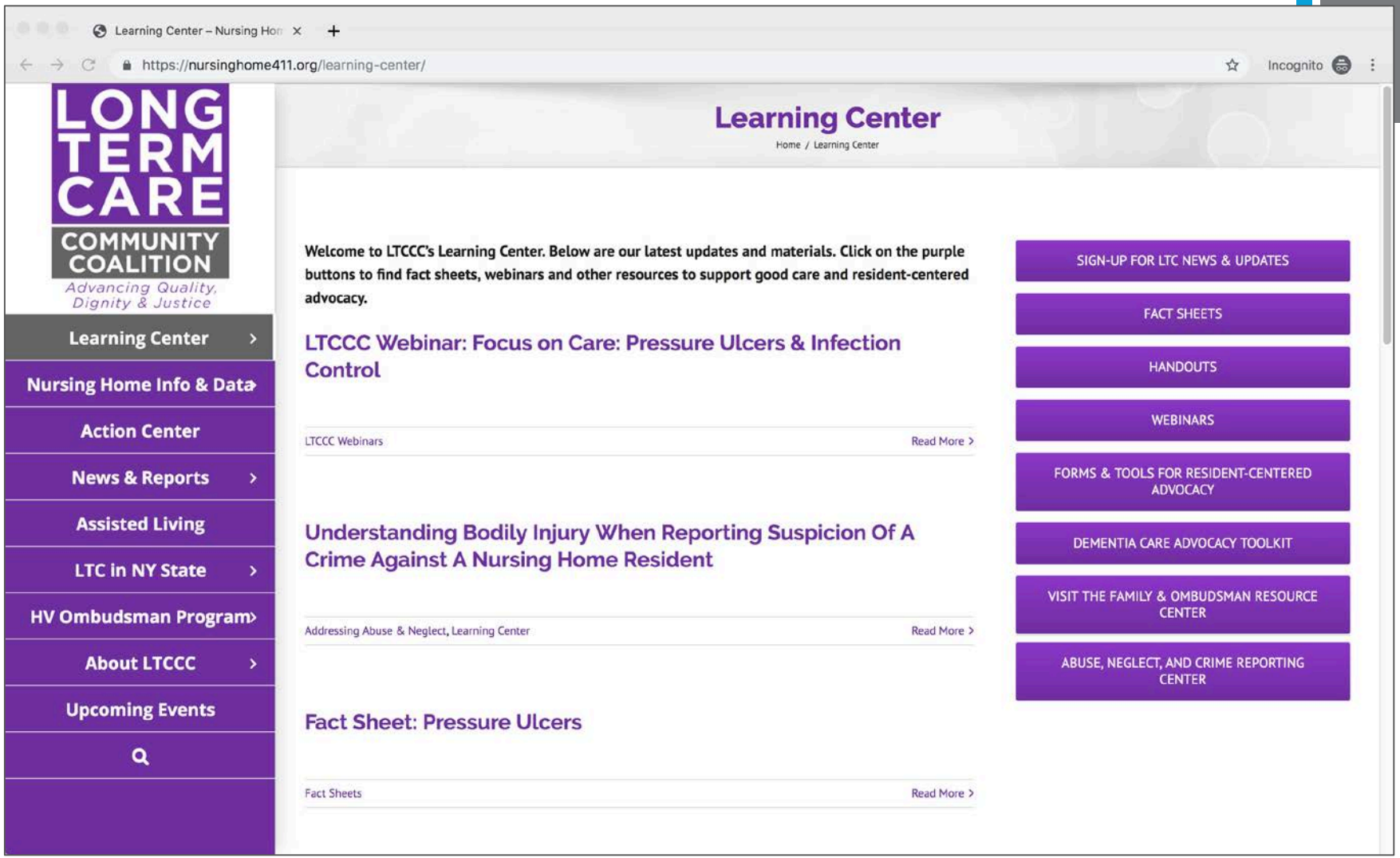
At hearing:

- Is there a dispute of the charges?
- Is there an appeal of a denial of benefits?
- Are funds actually available and is the resident refusing to cooperate with the facility in obtaining the funds?

+

# Improving Resident Care:
Information, Tools, & Resources

# www.nursinghome411.org



# Handouts

## RESIDENT CARE PLAN

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. To meet these goals, nursing homes are required to develop an individualized care plan for each resident, based on careful assessment of each resident to understand his or her specific care needs.

### Standards of Care

- **Provide individualized care plan.** Nursing homes must develop a person-centered baseline care plan for each nursing home resident within 48 hours of admission.
- **Resident assessment.** A facility must make an assessment of the resident's capacity, needs, and preferences. The assessment must include a wide range of resident needs and abilities, including customary routine, cognitive patterns, mood, ability to and methods of communication, and physical, dental, and nutritional status.
- **Assessment-based plan.** The care plan must be based on the assessment. In other words, it must come from the resident's needs and abilities, not the services or staffing levels which the nursing home decides to provide based on its financial (or other) priorities.

### Resources

1. The Learning Center on LTCCC's website, www.nursinghome411.org, contains easy-to-use fact sheets on many of the nursing home standards of care most relevant to residents. See http:// nursinghome411.org/fact-sheet-resident-care-planning/.
2. LTCCC's website has a section with free, easy-to-use forms for resident-centered advocacy, including a resident assessment worksheet. See https://nursinghome411.org/forms-resources-for-resident-centered-advocacy/.

## INFECTION CONTROL AND PREVENTION

Infection prevention and control programs protect residents from preventable harm, injury, and death. Infections continue to be a leading cause of death, needless suffering, and expense among nursing home residents.

### Standards of Care

- **Implement an infection prevention and control program.** Nursing homes must have a "system for preventing, identifying, reporting, investigating, and controlling infections."
- **Develop written policies and procedures.** Nursing homes are required to have policies to address infections, such as providing instructions on how to determine whether someone is infected.
- **Record incidents.** Nursing homes must implement a system for documenting incidents and corrective actions.
- **Practice the safe management of linens.** Nursing homes "must handle, store, process, and transport linens so as to prevent the spread of infection."
- **Conduct annual reviews of the program.** Nursing homes must review their infection control policies every year and update as necessary.

### Resources

1. The Agency for Healthcare Research and Quality (AHRQ) advises staff to clean their hands. See https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/cauti-ltc/modules/resources/guides/infection-prevent.html.
2. LTCCC issue alert describing federal requirements for infection control in nursing homes. See https://nursinghome411.org/ltccc-issue-alert-infection-control-prevention/.
3. LTCCC Report finds that infection control deficiencies were cited more than other deficiencies over a three year period, based on Nursing Home Compare data. See http://nursinghome411.org/identification-of-resident-harm-in-nursing-home-citations/.

# Fact Sheets

LONG TERM CARE
COMMUNITY COALITION
*Advancing Quality, Dignity & Justice*

## 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 boney 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 resources, please visit www.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.

# + Issue Alerts



LONG TERM CARE
COMMUNITY COALITION
*Advancing Quality, Dignity & Justice*

## Issue Alert: Infection Prevention and Control

### I. Why are Infection Control Requirements Important to Residents?

Infection prevention and control programs protect residents from preventable harm, injury, and death. Sadly, despite strong regulatory requirements to protect residents, infections continue to be a leading cause of death, needless suffering, and expense among nursing home residents.[1] According to the Office of Disease Prevention and Health Promotion, 380,000 nursing home residents die each year due to health care-associated infections.[2] Preventable reasons for the spread of infection include deficient nursing home practices, such as staff not washing their hands or sterilizing equipment before providing resident care.

Note to Readers:

LTCCC Issue Alerts provide basic information about an issue of concern to nursing home residents.

For further information, please see the Resources and references at the end of the Alert, as well as our website, www.nursinghome411.org.

### II. What are the Infection Control Requirements?

The federal Nursing Home Reform Law requires each nursing home to **"establish and maintain an infection control program designed to provide a safe, sanitary, and comfortable environment in which residents reside and to help prevent the development and transmission of disease and infection."** The infection control program must **"be designed, constructed, equipped, and maintained in a manner to protect the health and safety of residents, personnel, and the general public."**[3] In order to be certified under Medicare and Medicaid, nursing homes must adhere to the following minimum standards of care in regards to infection prevention and control:

- **Implement an infection prevention and control program.** Nursing homes must have a "system for preventing, identifying, reporting, investigating, and controlling infections and communicable diseases for all residents, staff, volunteers, visitors, and other individuals providing services under a contractual arrangement based upon the facility assessment . . . following accepted national standards;"[4]
- **Develop written policies and procedures.** Nursing homes must have "[w]ritten standards, policies, and procedures for the program, which must include, but are not limited to:
  - A system of surveillance designed to identify possible communicable diseases or infections before they can spread to other persons in the facility;



  - When and to whom possible incidents of communicable disease or infections should be reported;
  - Standard and transmission-based precautions to be followed to prevent spread of infections;
  - When and how isolation should be used for a resident; including but not limited to:
    - The type and duration of the isolation, depending upon the infectious agent or organism involved, and
    - A requirement that the isolation should be the least restrictive possible for the resident under the circumstances.
  - The circumstances under which the facility must prohibit employees with a communicable disease or infected skin lesions from direct contact with residents or their food, if direct contact will transmit the disease; and
  - The hand hygiene procedures to be followed by staff involved in direct resident contact."[5]
- **Implement a system for documenting incidents and corrective actions.** Nursing homes must have a "system for recording incidents identified under the facility's IPCP and the corrective actions taken by the facility."[6]
- **Practice the safe management of linens.** Nursing home staff "must handle, store, process, and transport linens so as to prevent the spread of infection."[7]
- **Conduct annual reviews of the program.** Nursing homes must "conduct an annual review of its IPCP and update their program, as necessary."[8]

### III. How Prevalent are Infection Control Deficiencies?

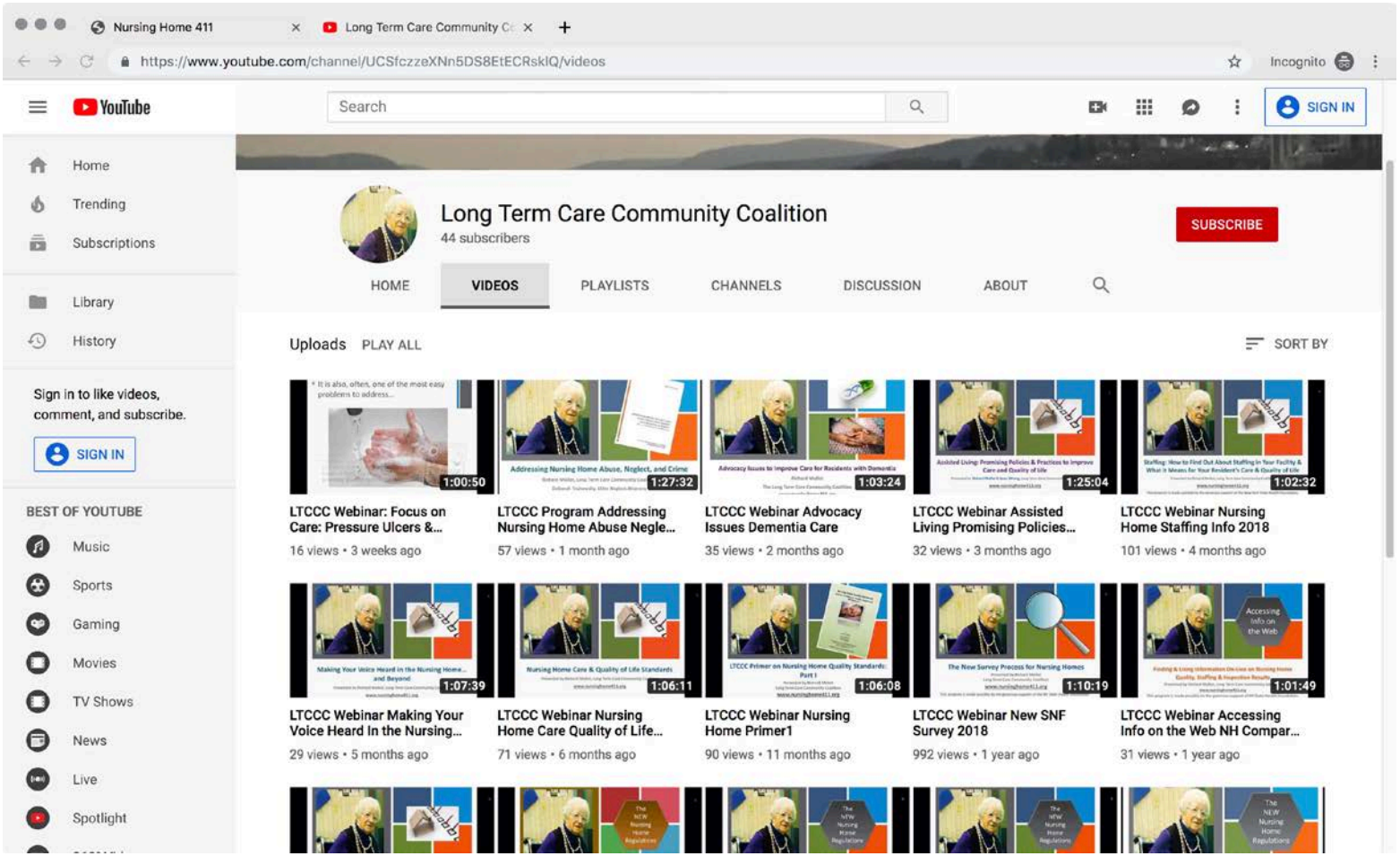
A 2014 report by the U.S. Department of Health and Human Services' Office of the Inspector General (OIG) found that an astounding 20 percent of Medicare nursing home residents experienced an "Adverse Event" within the first month of admission to a nursing home, with the harm occurring, on average, within 15 days after admission.[9] Infections accounted for 26 percent of these adverse events; the OIG classified the majority of these harmful events—52 percent—as "preventable."[10]

Data from Nursing Home Compare show that state surveyors have cited 20,190 infection control deficiencies over the last three inspection cycles (years). In total, infection control deficiencies account for nearly seven percent of all nursing home deficiencies on Nursing Home Compare over the last three inspection cycles (as of February 2018).

"Basic steps to prevent infections — such as washing hands, isolating contagious patients and keeping ill nurses and aides from coming to work — are routinely ignored in the nation's nursing homes, endangering residents and spreading hazardous germs."

-Jordan Rau, *Los Angeles Times* (Dec. 2017)

# Webinars



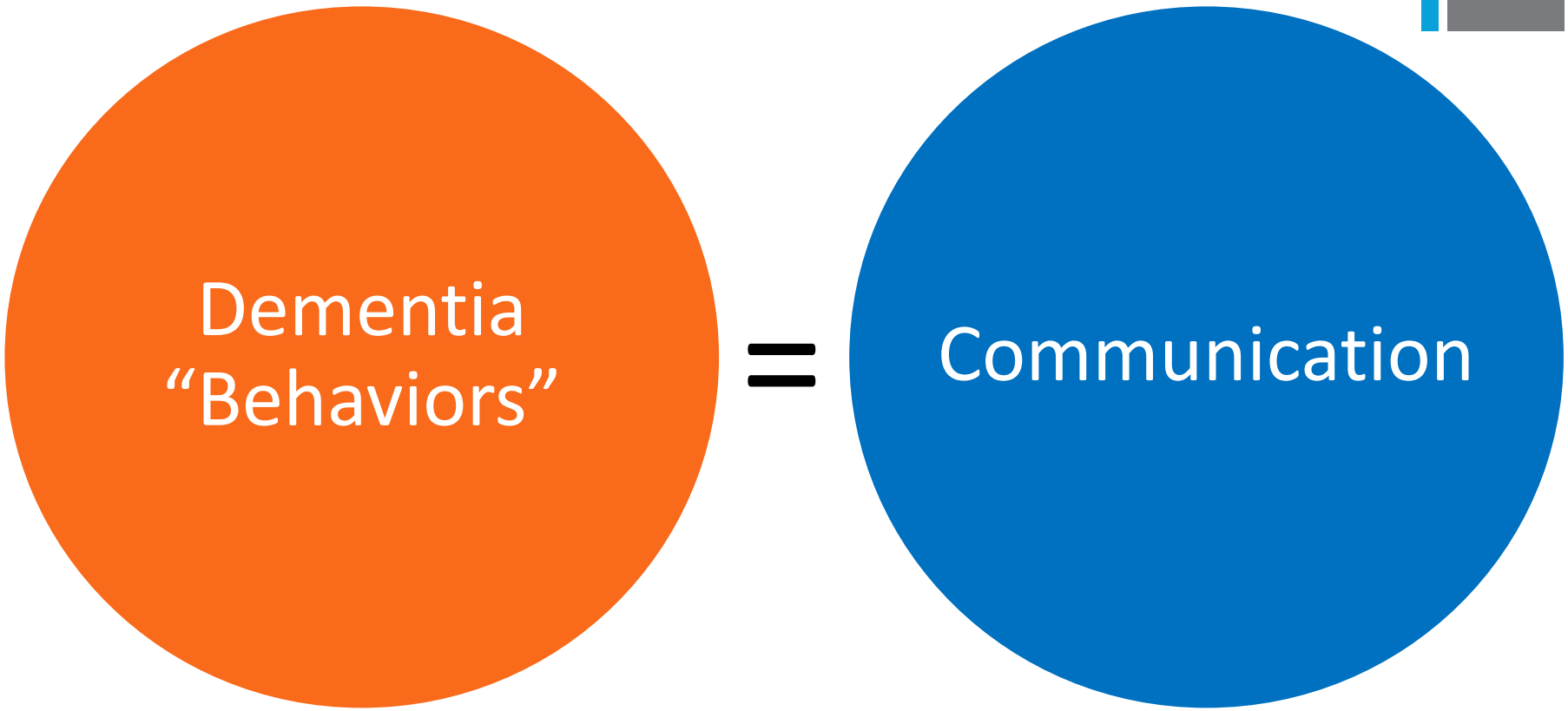

Email SARA@LTCCC.ORG to receive invites or click on the YouTube icon on our website to visit our library of past programs.

+

# Improving Care for Residents With Dementia:

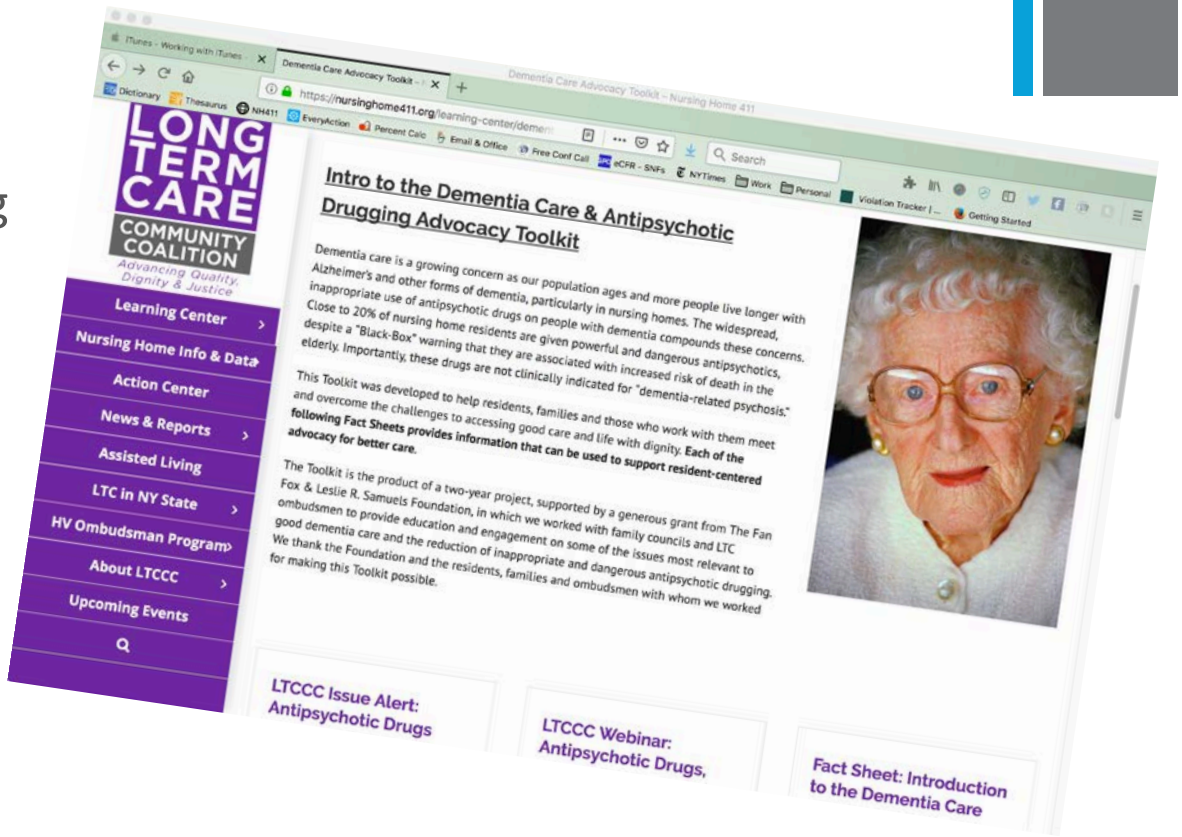
Information, Tools, & Resources

# #1 Point



# The Dementia Care Toolkit

- What should I look for when assessing a facility?
- What should I see going on in my facility?
- What do we have a right to expect **before** drugs are given to a resident?
- What do we have a right to expect **after** drugs are given?
- And more!



# The Dementia Care Toolkit

- Dementia Car Considerations
- Dementia Care Practices
- Dementia Care & Psychotropic Drugs
- Non-Pharmacological Approaches to Dementia Care
- Resident Dignity & Quality of Life
- Standards for a Safe Environment
- Resident Assessment & Care Planning
- Care Planning Requirements
- Informed Consent
- Resident & Family Recordkeeping
- Standards for People Providing Care
- Standards for Nursing Home Services
- Standard of Care to Ensure Resident Wellbeing

**Thank you to the Fan Fox & Leslie R. Samuels Foundation for supporting the development of this toolkit, and to the family councils who welcomed us to their meetings!**

+

## Making Your Voice Heard…

In the Nursing Home

# A Few Pointers….

- **Be polite.** Most people want to do a good job. Nobody likes to be attacked, or feel badly about the job they are doing. Though it is upsetting to be receiving poor care, or to see a loved one suffer, it is important to remember our goal: to improve care or conditions for the resident.
- **Know your rights.** See LTCCC's Learning Center for helpful fact sheets and other resources.
- **Work together** (whenever possible).
  1. Facility staff. Try to work cooperatively with staff. "These are my rights… how can we make it happen?"
  2. Join the resident or family council.
- **Keep good records.** It can be very hard to keep track of a concern or complaint, especially in a confusing or stressful situation. To help, LTCCC is putting together free, easy-to-use tools.

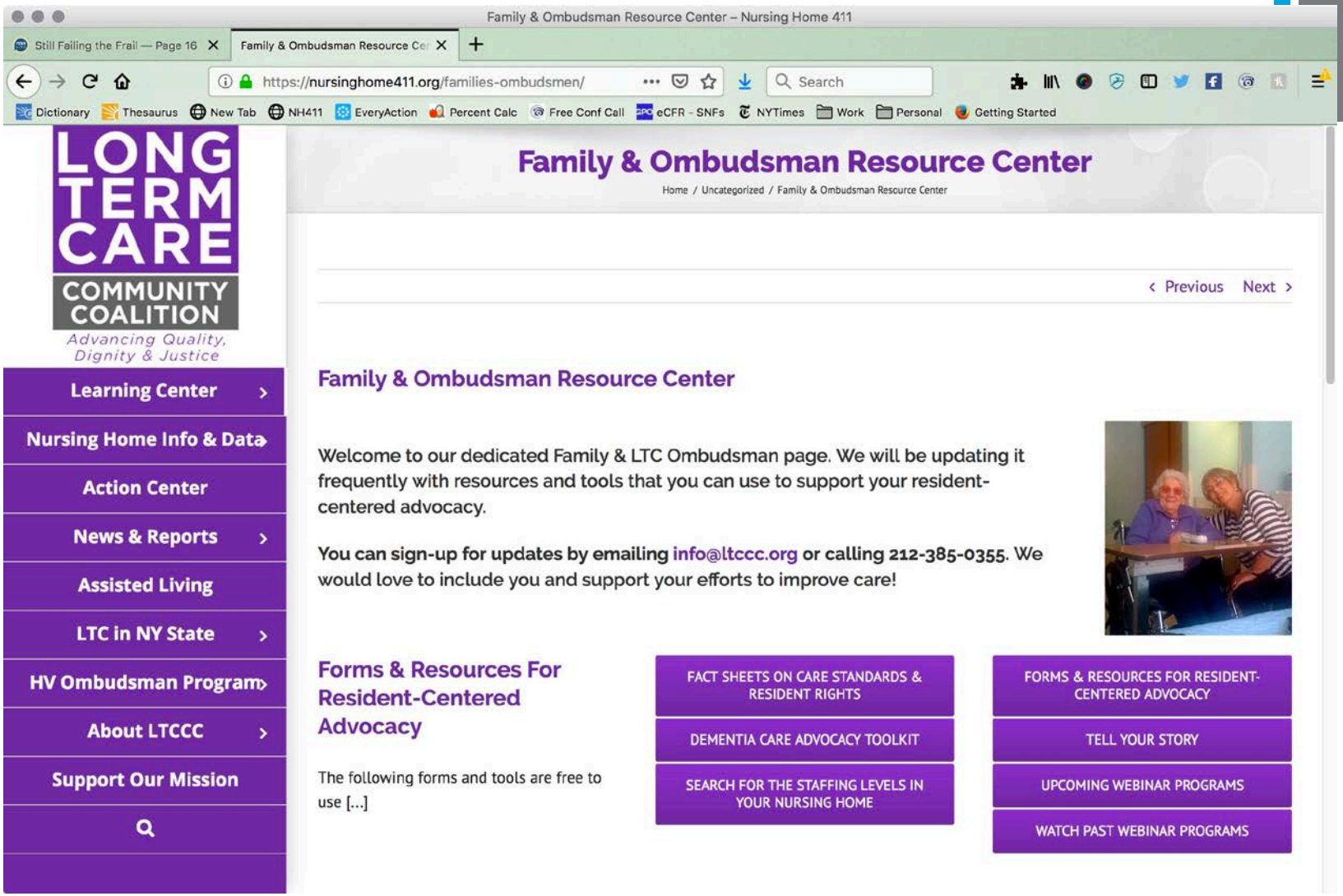
# Who to Speak to….

- **Care staff.** Start with those working closest to resident and work out from there. If a problem can be resolved with the cooperation of caregivers, great!
- **Grievance officer.** Every nursing home is now required to have a grievance officer who is responsible for taking complaints, leading any necessary investigations, and tracking them through to conclusion. Residents and their representatives have a right to a written decision.
- **LTC ombudsman.** The LTC ombudsman can help you to navigate and resolve problems. If your facility does not have a regular ombudsman visiting, you can contact the LTC Ombudsman office.
- **Resident & family councils.** As noted above (and throughout our resources) participating in a resident or family council can be a very effective vehicle for raising concerns about care or quality of life in your facility in a constructive way.

**Important Note:** These are some general suggestions. It is important, however, to always act in the best interest of the safety of residents, staff, and visitors.

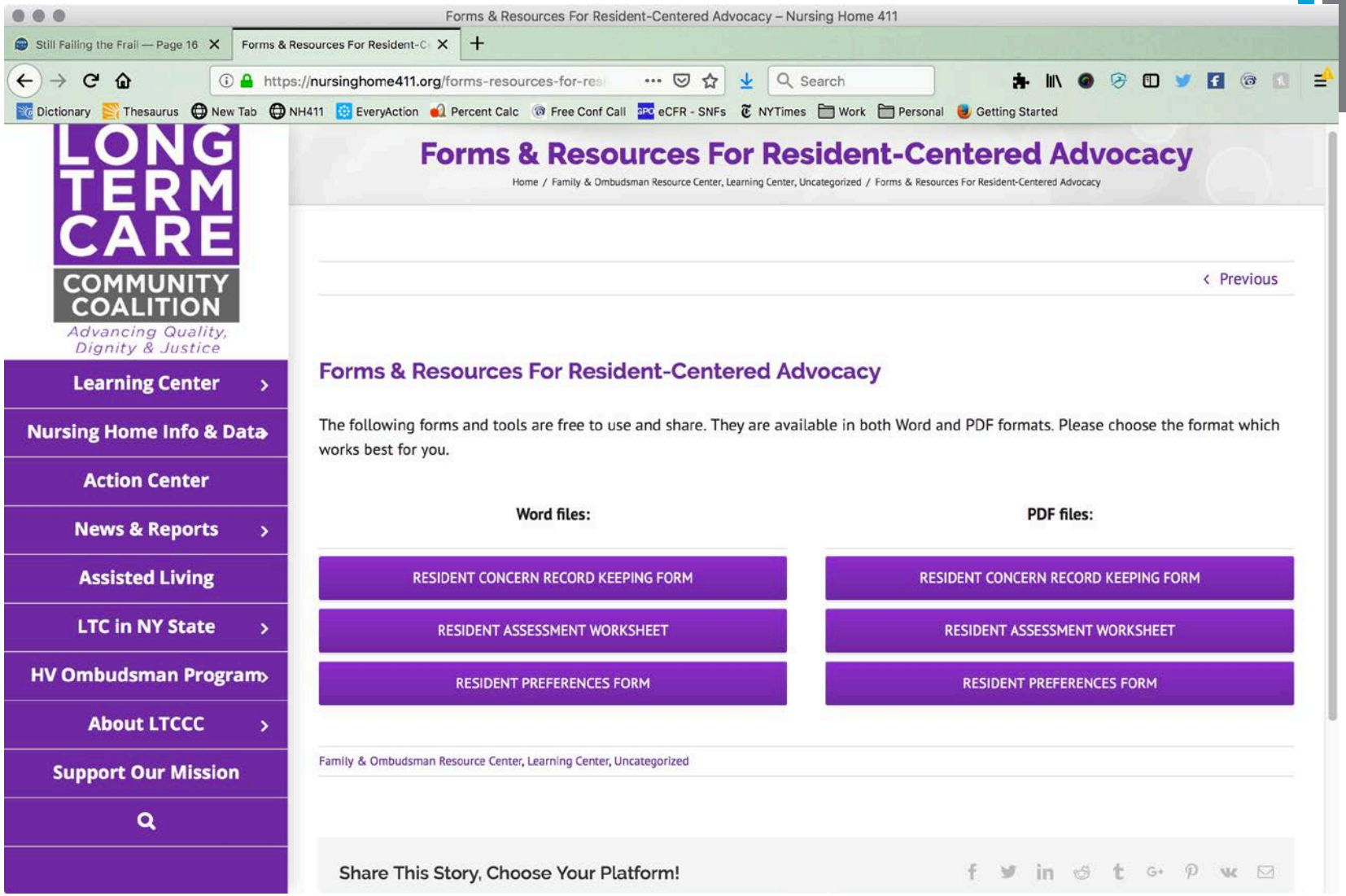
# Tools: Family & Ombudsman Resource Center





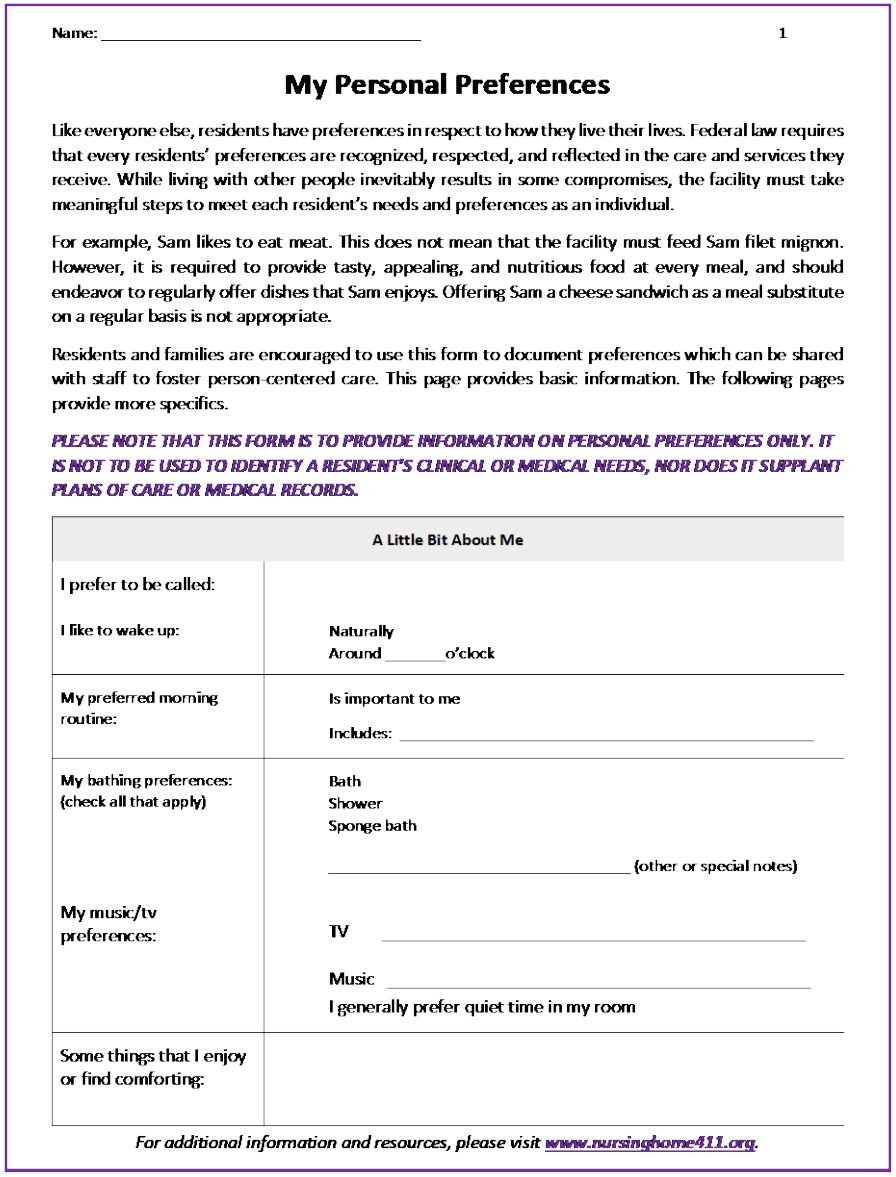
# Tools: Forms & Resources Page





# Resident Preferences Form





Name: _____ 1

## 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<br>Around _____o'clock |
| My preferred morning routine: | Is important to me<br>Includes: _____ |
| My bathing preferences: (check all that apply) | Bath<br>Shower<br>Sponge bath<br>_____(other or special notes) |
| My music/tv preferences: | TV _____<br>Music _____<br>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.*

Additional topics covered:

- Personal background
- Sleeping
- Dressing
- Grooming
- Activities
- TV & Music
- Social interactions
- Religious/spiritual

Form is available in both PDF & Word formats. Add as little or as much information as you like.

# Resident Concern or Complaint Form



**Today's Date: _____**

## Record-Keeping Form For Resident Concerns

This form can be used to keep personal 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:**

**Staff Person(s) Spoken To:**

**Response/Plan of Action from Staff:**

**Actions Taken:**

**Today's Date: _____**

*- - - Make as Many Copies of This Page as Necessary to Track Your Concern - - -*

**Issue (Update):**

**Staff Person(s) Spoken To:**

**Response/Plan of Action from Staff:**

**Actions Taken:**

**Today's Date: _____**

**Issue (Update):**

**Staff Person(s) Spoken To:**

**Response/Plan of Action from Staff:**

**Actions Taken:**

For additional information and resources, please visit
www.nursinghome411.org.

# Fact Sheet: Resident Assessment & Care Planning



**LONG TERM CARE COMMUNITY COALITION**

*Advancing Quality, Dignity & Justice*

**CONSUMER FACTSHEET: RESIDENT ASSESSMENT & 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. YOU can use these standards as a basis for advocating in your nursing home.
Following are two important standards for residents assessment and care planning with information that can help you understand and use them to advocate for your resident. [Note: The brackets provide the relevant federal regulation (CFR) and F-tag (category of deficiency).]

## I. RESIDENT ASSESSMENT [42 CFR 483.20 F-636]

- *The facility must conduct initially and periodically a comprehensive, accurate, standardized reproducible assessment of each resident's functional capacity.*
- *A facility must make a comprehensive assessment of a resident's needs, strengths, goals, life history and preferences, using the resident assessment instrument (RAI) specified by CMS.*
- *The assessment must include at least the following:*
  - ✓ Identification and demographic information.
  - ✓ *Customary routine.*
  - ✓ *Cognitive patterns.*
  - ✓ *Communication.*
  - ✓ *Vision.*
  - ✓ *Mood and behavior patterns.*
  - ✓ *Psychosocial well-being.*
  - ✓ *Physical functioning and structural problems.*
  - ✓ *Continence.*
  - ✓ *Disease diagnoses and health conditions.*
  - ✓ *Dental and nutritional status.*
  - ✓ *Skin condition.*
  - ✓ *Activity pursuit.*
  - ✓ *Medications.*
  - ✓ *Special treatments and procedures.*
  - ✓ *Discharge planning.*
  - ✓ *Documentation of summary information regarding the additional assessment performed through the resident assessment protocols.*
- *Documentation of participation in assessment. The assessment process must include direct observation and communication with the resident, as well as communication with licensed and nonlicensed direct care staff members on all shifts.*

Use this checklist to identify what is important to YOU when you have a resident assessment!

## II. COMPREHENSIVE PERSON-CENTERED CARE PLANNING [42 CFR 483.21]

*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. 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…*

*A comprehensive care plan must be…Developed within 7 days after completion of the comprehensive assessment.*

IMPORTANT NOTE: The new federal nursing home standards greatly expanded expectations for care planning. See the "LTCCC Factsheet Care Planning Requirements" for important details on how care plans must be developed and carried out.

**BASIC CONSIDERATION TO KEEP IN MIND**

- ☐ A facility must make an assessment of the resident's capacity, needs and preferences.
- ☐ The assessment must include a wide range of resident needs and abilities, including customary routine, cognitive patterns, mood, ability to and methods of communication, physical, dental and nutritional status.
- ☐ A facility is expected to primarily rely on direct observation and communication with the resident in order to assess his or her functional capacity.
- ☐ In addition to direct observation and communication with the resident, the facility must use a variety of other sources, including communication with care staff on all shifts.
- ☐ A resident's care plan "must describe… the services to be furnished to attain or maintain the resident's highest practicable physical, mental and psychosocial well-being…."
- ☐ The care plan must be based on the assessment. In other words, it must come from the resident's needs and abilities, not the services or staffing levels which the nursing home decides to provide based on its financial (or other) priorities.

**RESOURCES**

WWW.NURSINGHOME411.ORG. LTCCC's website includes materials on the relevant standards for nursing home care, training materials and other resources.

# Resident Assessment Planning Form



## Resident Assessment Planning Form

Nursing homes are required to conduct initially and periodically a comprehensive and accurate assessment of each resident's functional capacity. Federal law requires that it identify and respond to "a resident's needs, strengths, goals, life history and preferences." It is very important because it forms the basis for a resident's care plan, which outlines to services the facility promises to provide.

Federal standards also state "that the assessment process must include direct observation and communication with the resident, as well as communication with licensed and nonlicensed direct care staff members on all shifts." The purpose of this form is to assist residents, families, and those working with them to prepare for and participate effectively in the assessment process. It can be used to identify areas of concern related to the required components of the assessment.

Identification & Demographic Background:

Customary Routine:

Cognitive Patterns or Issues (e.g., memory loss, dementia, Alzheimer's, etc…):

Communication Challenges or Problems:

Vision Problems (e.g., blurry vision, floaters, flashes, etc…):

Mood or Behavioral Concerns (e.g., depression, anxiety, anger, etc…):

Concerns with Psychosocial Well-being (e.g., appropriate activities, social environment, etc…):

Physical Functioning and Structural Problems (e.g., trouble walking, backaches, arthritis, etc…):

**For additional information and resources, please visit**
**www.nursinghome411.org**

Continence Issues (e.g., bladder or bowel function, constipation, relying on assistance to go to the bathroom, etc…):

Disease diagnoses and health conditions:

Dental Problems or Concerns (e.g., toothaches, dental hygiene concerns, dentures, etc…):

Nutritional Concerns (e.g., weight loss, lack of interest in eating, difficulty eating, etc…)

**Skin Conditions (e.g., pressure ulcer concerns, itching, bruises, abnormal lumps, sore areas, etc…):**

**Activities (e.g., are activities engaging for resident, tailored to mental and physical abilities, etc…):**

**Medication Issues or Concerns (e.g., receiving antipsychotic drugs off-label, not receiving medications to relieve pain or anxiety, etc…):**

**Special Treatments and Procedure Concerns (e.g., staff members are not mindful of resident's food allergies, facility does not provide vegetarian options for meals, etc…):**

**If you have any further issues or concerns not described earlier, please write them below:**

**For additional information and resources, please visit**
**www.nursinghome411.org**

+

## Making Your Voice Heard…

Beyond the Nursing Home

# Tell Your Story



**Tell Your Story About Nursing Home or Assisted Living Care**

A few background questions.

**Thank you for taking the time to tell your story. Hearing from you helps us to provide a strong voice for better care and life with dignity for residents. Please note that we will never divulge any resident's name, or the name or location of a facility, unless you give us specific permission to do so.**

* 1. Are you a:

- ◯ Resident
- ◯ Staff Person
- ◯ Family Member
- ◯ Ombudsman
- ◯ Other (please specify)

* 2. Type of facility.

- ◯ Nursing Home
- ◯ Assisted Living/Adult Home
- ◯ Other (please specify)

* 3. Is the experience you are writing about positive or negative?

- ◯ Positive
- ◯ Negative

* 4. Did the situation involve abuse, neglect, or other problem? Please select all that apply:

- ☐ Neglect
- ☐ Unwanted Discharge From the Facility
- ☐ Medication
- ☐ Emotional Abuse
- ☐ Food or Dining Issue
- ☐ Communication Problem
- ☐ Physical Abuse
- ☐ Sexual Abuse
- ☐ Theft or Loss

Other (please specify)

5. Did the situation raise concerns about the care the resident was receiving?

- ◯ Yes
- ◯ No

6. Did the situation raise concerns about the safety of the resident?

- ◯ Yes
- ◯ No

1

**Tell Your Story About Nursing Home or Assisted Living Care**

Please tell your story here.

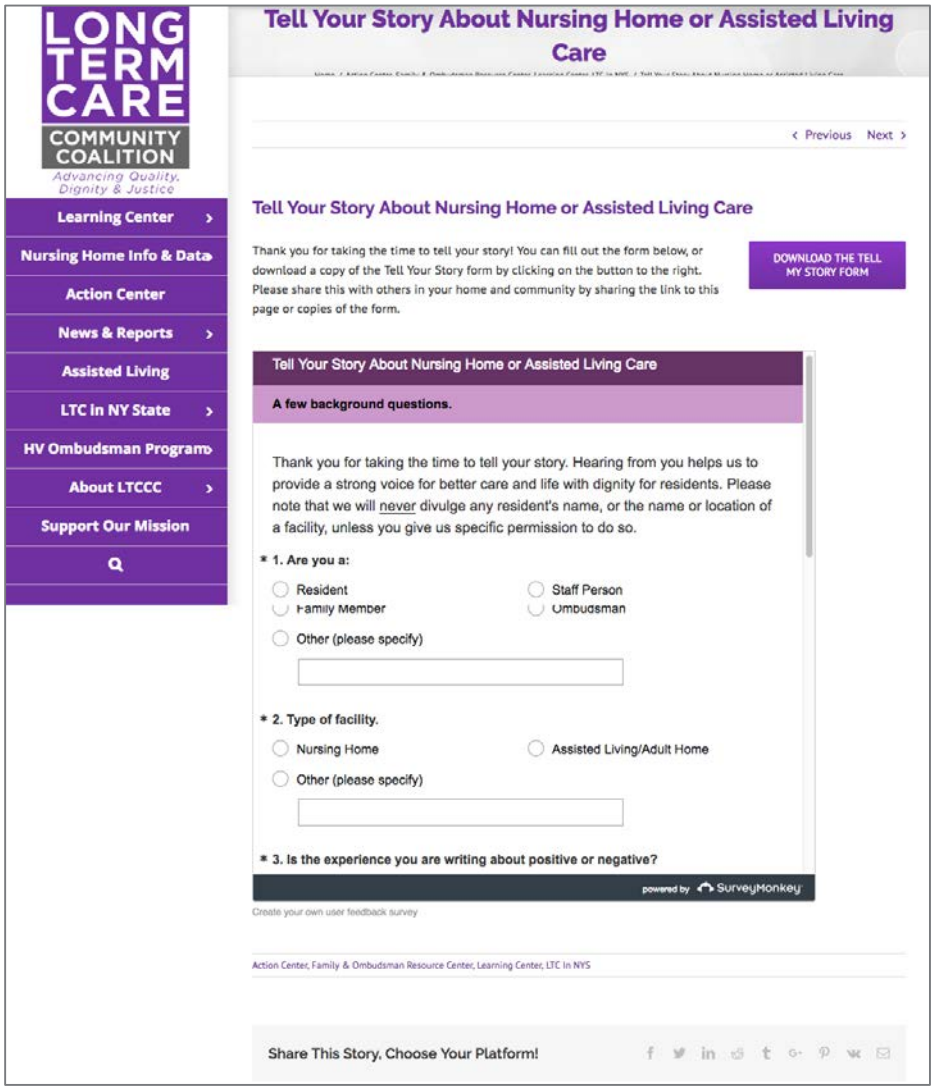
*

at matters to you, whether it is about a good experience or bad experience.

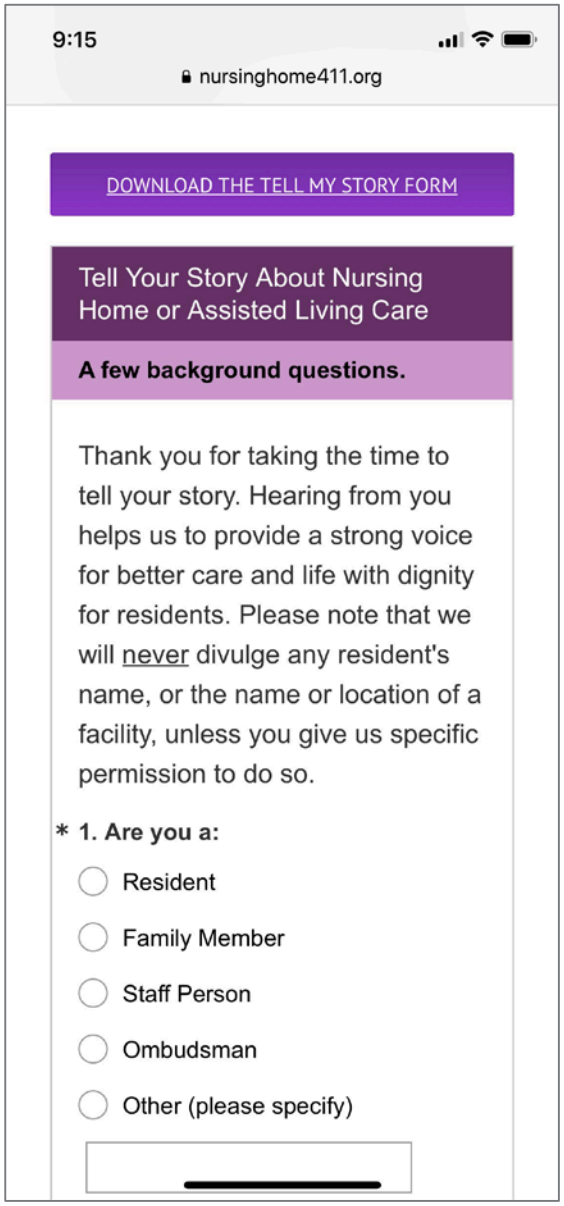
2

Visit www.nursinghome411.org to fill out or download copies of the form.

# Tell Your Story

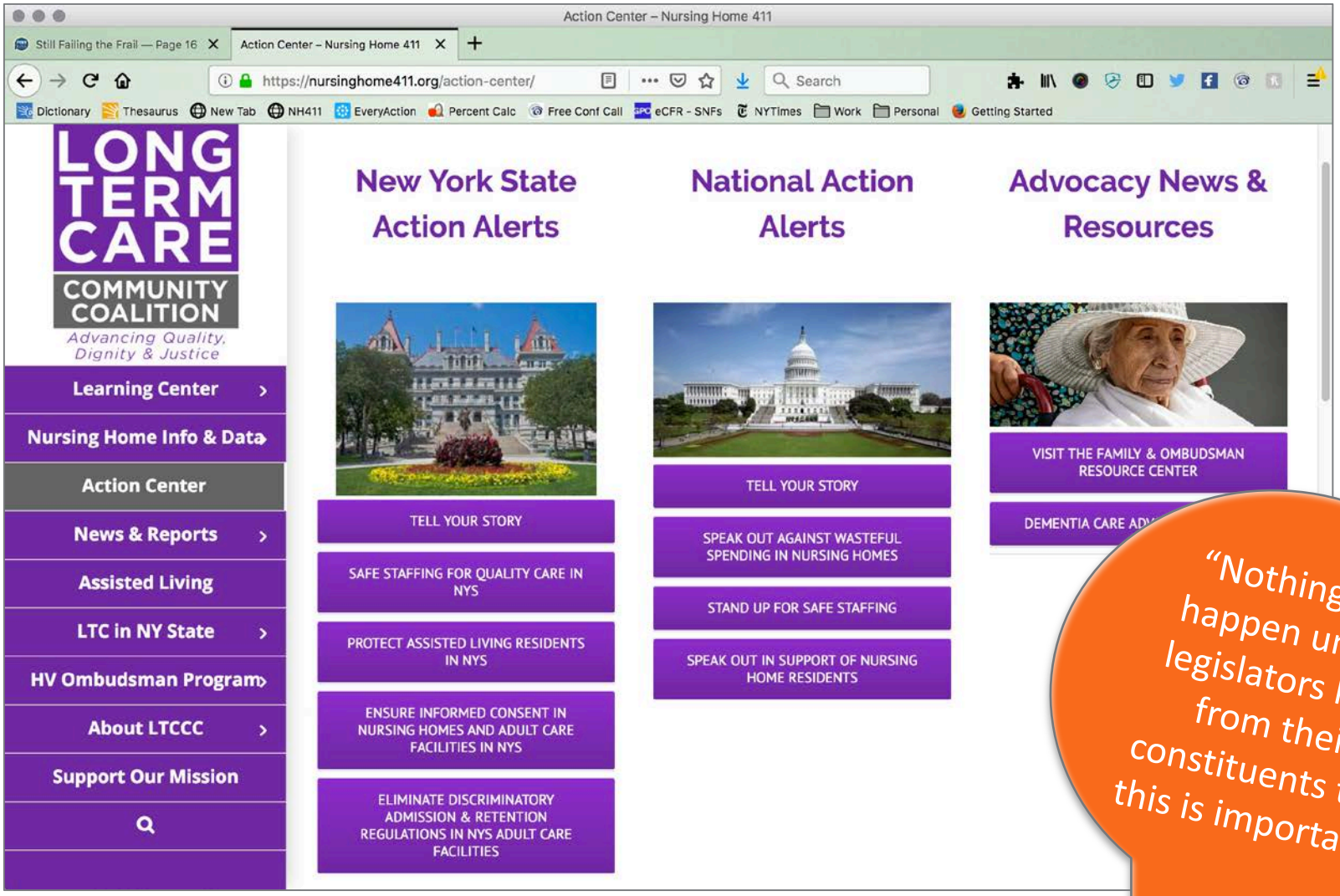



Computer Screenshot




iPhone Screenshot

# Speak Out to Policymakers



# Sample Alert



LONG TERM CARE
COMMUNITY COALITION
*Advancing Quality, Dignity & Justice*

## STAND UP FOR SAFE STAFFING

Staffing is critical to quality care and dignity for nursing home residents. Yet numerous studies have shown that the majority of nursing homes fail to have sufficient staff to meet a typical resident's needs. We wouldn't allow a nursing home to admit 100 residents if it only had 60 beds. Why do we allow nursing homes to admit as many residents as they want, with no minimum staffing requirements, even when the facility has a history of substandard care?

Please send a quick message now to let your political leaders know that the time has come for safe staffing standards in nursing homes.

Not **Richard Mollot?** Click here to logout. fastAction

**Contact Information**

Prefix (Optional): Mr.
First Name: Richard
Last Name: Mollot
Street Address: 1 Pennsylvania Plaza, Suite 6252
Postal Code: 10119
City: New York
State/Province: NY
Email: richard@ltccc.org
Home Phone (Optional): 212-385-0355

☑ Update my *Fast***Action** profile with this information.

Personalize your subject

I am writing to you today regarding a very important issue, Safe Staffing for Nursing Home Residents.

Dear [elected official],

Personalize your message

I am writing to you in regard to nursing home staffing, one of the most important factors in the quality of care that nursing home residents receive and the quality of life that they enjoy. Sadly, I have learned that nursing homes all too often fail to provide the adequate staffing that is necessary to meet the needs of their residents. As a result, vulnerable residents suffer.

Recently, The New York Times found that nursing homes actually have less staffing than they were previously reporting to the Centers for Medicare & Medicaid Services (CMS). A new reporting system based on payroll-based data, rather than the previously used self-reported data, has shown that seven out of ten nursing homes have lower staffing than previously reported to the public. The new, verifiable data indicate that some nursing homes are even failing to provide any registered nurse care at times. I hope you will agree that this is a significant betrayal of the public trust.

Every nursing home is paid, and required by law, to have sufficient staff with the competencies and skills needed to meet the care needs of each resident. However, these minimum standards are often undermined by poor enforcement or manipulation, as The New York Times article suggests. Given this reality, nursing home residents need the protection of more robust staffing and enforcement requirements.

Years of research and the experiences of millions of nursing home residents and their families point to the need for safe staffing

Sincerely,
[Your information here]

Submit

http://www.nursinghome411.org

Powered by EveryAction

# + Coming Up

## The Federal Nursing Home Requirements: Heading to Phase 3 Implementation (11/19)

## August 20 at 1pm Eastern

**Attend Any LTCCC Program in Two Easy Ways**:

**1**) To join the online meeting, about five minutes before the scheduled time of the meeting, go to the link below and follow the prompts to join the meeting.

Online Meeting Link: **https://join.freeconferencecall.com/richardmollot**.

**2**) To participate by phone, at the scheduled time of the meeting call (712) 770-4010. When prompted, enter the Access Code, 878277, followed by the pound (#) key. Press *6 to mute or unmute your phone line.

If you would like to receive a copy of the webinar handouts, please email sara@ltccc.org (noting the date of the program).

# Thank You For Joining Us Today!

Visit nursinghome411.org/join/ if you would like to…

- Receive alerts for future programs or
- Sign up for our newsletter and alerts.

You can also…

- Join us on **Facebook** at www.facebook.com/ltccc
- Follow us on **Twitter** at www.twitter.com/LTCconsumer
- Visit us on the **Web** at www.nursinghome411.org.

**For LTC Ombudsmen in NY State**

If you would like us to let your supervisor know that you attended this training program, please take the quick survey at:
**https://www.surveymonkey.com/r/ltccc-ltcop1**

**For Family Members in NY State**

connect with the Alliance of NY Family Councils at **www.anyfc.org** (or email info@anyfc.org).


Questions?
Comments?