



The National

CONSUMER VOICE

for Quality Long-Term Care

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

OFFICE HOUR

LAST WEDNESDAY OF
EVERY MONTH



Regulations, Rights, and Reality: Addressing Psychotropic Misuse in Long-Term Care Facilities

June 24, 2026

Welcome

- ▶ This call is being **recorded**.
- ▶ Use the **chat feature** to submit comments or respond to questions from speakers or other attendees.
- ▶ Links to **resources** discussed will be shared in the chat box. Materials and the call recording will be posted on the NORC website.

Speakers



Lori Smetanka
Executive Director

National Consumer Voice
for Quality Long Term Care



Richard J. Mollot
Executive Director

Long Term Care
Community Coalition

Agenda

- ▶ Psychotropic Medications
- ▶ Federal Regulations/Using Data
- ▶ Office of Inspector General Reports
- ▶ Advocating for Better Care
- ▶ Resources and Questions



Psychotropic Medications

What are psychotropic medications?

- ▶ Appendix PP [§483.45\(c\)\(3\)](#)

- ▶ A psychotropic drug is any drug that affects brain activities associated with mental processes and behavior. These drugs include, but are not limited to, drugs in the following categories: (i) Anti-psychotic; (ii) Anti-depressant; (iii) Anti-anxiety; and (iv) Hypnotic.

- ▶ Psychotropic drugs affect mental activity, emotion, and behavior (e.g., antipsychotics, antidepressants, mood stabilizers)

Off-label Uses in Long-Term Care Facilities

- ▶ Despite known dangers, antipsychotic drugs are commonly prescribed to elder nursing facility residents for uses not approved by the FDA
- ▶ Often to control unwanted/challenging behavior caused by dementia
- ▶ To avoid increased staffing and training for non-pharmacological interventions to modify these behaviors
- ▶ Serious concerns that the risks and alternative interventions are not given appropriate consideration and consent not obtained

Impact of Psychotropic Drugs

- ▶ Side effects can be very harmful for older adults with dementia – lower quality of life
 - ▶ Increased vulnerability to infections
 - ▶ Excessive sedation, lethargy, dizziness, unsteadiness
 - ▶ Tremors and rigidity, body restlessness
 - ▶ Reduced well-being, loss of appetite, social withdrawal
 - ▶ Accelerated cognitive decline



Federal Requirements/Using Data



Consumer Voice/NORC AP Drugging Program

Richard Mollot

Long Term Care Community Coalition

www.nursinghome411.org



The Long Term Care Community Coalition?

- **LTCCC**: Nonprofit organization dedicated to improving care & quality of life for the elderly & adult disabled in long-term care (LTC).
- **Our primary focus**: People who live in nursing homes & assisted living.
- **What we do**:
 - Policy & data analysis;
 - Systems advocacy;
 - Education of consumers and families, LTC Ombudsmen and other stakeholders.
- **Website**: www.nursinghome411.org.



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Antipsychotic Drugs & Dementia Care

Regulatory Standards and Requirements

+ Important to keep in mind...

The focus of our discussion – and of the federal standards – is on nursing home care.

HOWEVER, this is a serious problem for people in assisted living and home care, too.

Studies have found that:

- 76% of assisted living residents have a documented diagnosis of dementia.
- 37% of those individuals were being given antipsychotic drugs.
- Residents in an assisted living that had a “memory care unit” were more likely to be treated with both dementia medications and antipsychotic drugs.



Good
Dementia
Care No
Matter
Where!

+

The Nursing Home Reform Law

- The law passed in 1987.
- **Every** nursing home that participates in Medicaid/Medicare agrees to meet or exceed the standards laid out in the Reform Law and its implementing regulations.
- Participation in Medicaid/Medicare is voluntary. Nursing homes that do not wish to meet these standards are free to run private facilities.



+ The Nursing Home Reform Law

- The federal law requires that every nursing home resident is provided the care and quality of life services sufficient to attain and maintain their **highest practicable physical, emotional, & psychosocial well-being**.
- The law emphasizes **individualized, patient-centered care**.





Why are the laws & regs important?

- The Reform Law proscribes the use of psychotropic drugs as chemical restraints to control or sedate residents for the convenience of staff.
- In May 2011, the U.S. DHHS Inspector General said **nursing home residents and their families should be “outraged”** by his office’s report that well over a quarter of a million residents were receiving antipsychotic drugs for medically unaccepted, off-label uses.
- In a 2012 review of resident records, his office found that 91% did not contain evidence that the resident or the resident’s family or legal representative participated in the care planning process. Every resident in this study was administered an antipsychotic drug.
- Subsequent updates to federal regulations strengthen expectations for **good dementia care** and **avoiding inappropriate drugging**.

+ The Law: Residents' Rights

- **Freedom from Chemical Restraints:** It is against the law to give antipsychotic drugs or other medications unless they benefit the resident. Drugs cannot be given to make things more convenient for staff.
- **Dignity:** Every resident, including those with dementia, has the right to be treated with dignity and respect and to live in a comfortable environment.
- **Necessary Care & Services:** Every resident, no matter who pays for her care, has the right to receive the care and services necessary to attain and maintain highest possible well-being and functioning.
- **Informed Decision-Making:** Residents have the right to be informed about the risks and benefits of any medication or treatment in language he or she can understand.
- **Right to Refuse:** Residents have the right to refuse a medication or treatment.

Factsheet on Dementia Care & Drugging Standards

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?

III. Psychotropic Drugs [42 CFR 483.45(e) F-758]

Based on a comprehensive assessment of a resident, the facility **must** ensure that-

- Residents who have not used psychotropic drugs are not given these drugs unless the medication is necessary to treat a specific condition as diagnosed and documented in the clinical record;
- Residents who use psychotropic drugs receive gradual dose reductions, and behavioral interventions, unless clinically contraindicated, in an effort to discontinue these drugs;
- Residents do not receive psychotropic drugs pursuant to a PRN order unless that medication is necessary to treat a diagnosed specific condition that is documented in the clinical record; and
- PRN orders for psychotropic drugs are limited to 14 days.¹

BASIC DEMENTIA CARE REQUIREMENTS & EXPECTATIONS

1. **Obtain details about the person's behaviors** (nature, frequency, severity, and duration) and risks of those behaviors, and discuss potential underlying causes with the care team and (to the extent possible) resident, family or representative;
2. **Exclude potentially remediable causes of behaviors** (such as medical, medication-related, psychiatric, physical, functional, psychosocial, emotional, environmental) and determined if symptoms were severe, distressing or risky enough to adversely affect the safety of residents;
3. **Implement non-pharmacological approaches to care** to understand and address behavior as a form of communication and modify the environment and daily routines to meet the person's needs;
4. **Implement the care plan consistently** and communicated across shifts and among caregivers and with the resident or family/representative (to the extent possible); and
5. **Assess the effects of the approaches**, identify benefits and complications in a timely fashion, involve the attending physician and medical director (as appropriate for the resident's well-being) **and adjust treatment accordingly**.

RESOURCES

- WWW.NURSINGHOME411.ORG. LTCCC's website includes materials on the relevant standards for nursing home care, including our Tool-Kit for a listing of antipsychotic drug names and other resources.
- WWW.THECONSUMERVOICE.ORG. The Consumer Voice has numerous materials and resources for residents, family members and LTC Ombudsmen.

¹ There is a limited exception "if the attending physician or prescribing practitioner believes that it is appropriate for the PRN order to be extended beyond 14 days, he or she should document their rationale in the resident's medical record and indicate the duration for the PRN order." PRN orders for anti-psychotic drugs are limited to 14 days and cannot be renewed unless the attending physician or prescribing practitioner evaluates the resident for the appropriateness of that medication.

The Dementia Care Toolkit

- Dementia Care 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



www.nursinghome411.org/learn/dementia-care-advocacy-toolkit/



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Using the Data

Finding out the antipsychotic drugging levels in your nursing home, and those in your community and state.

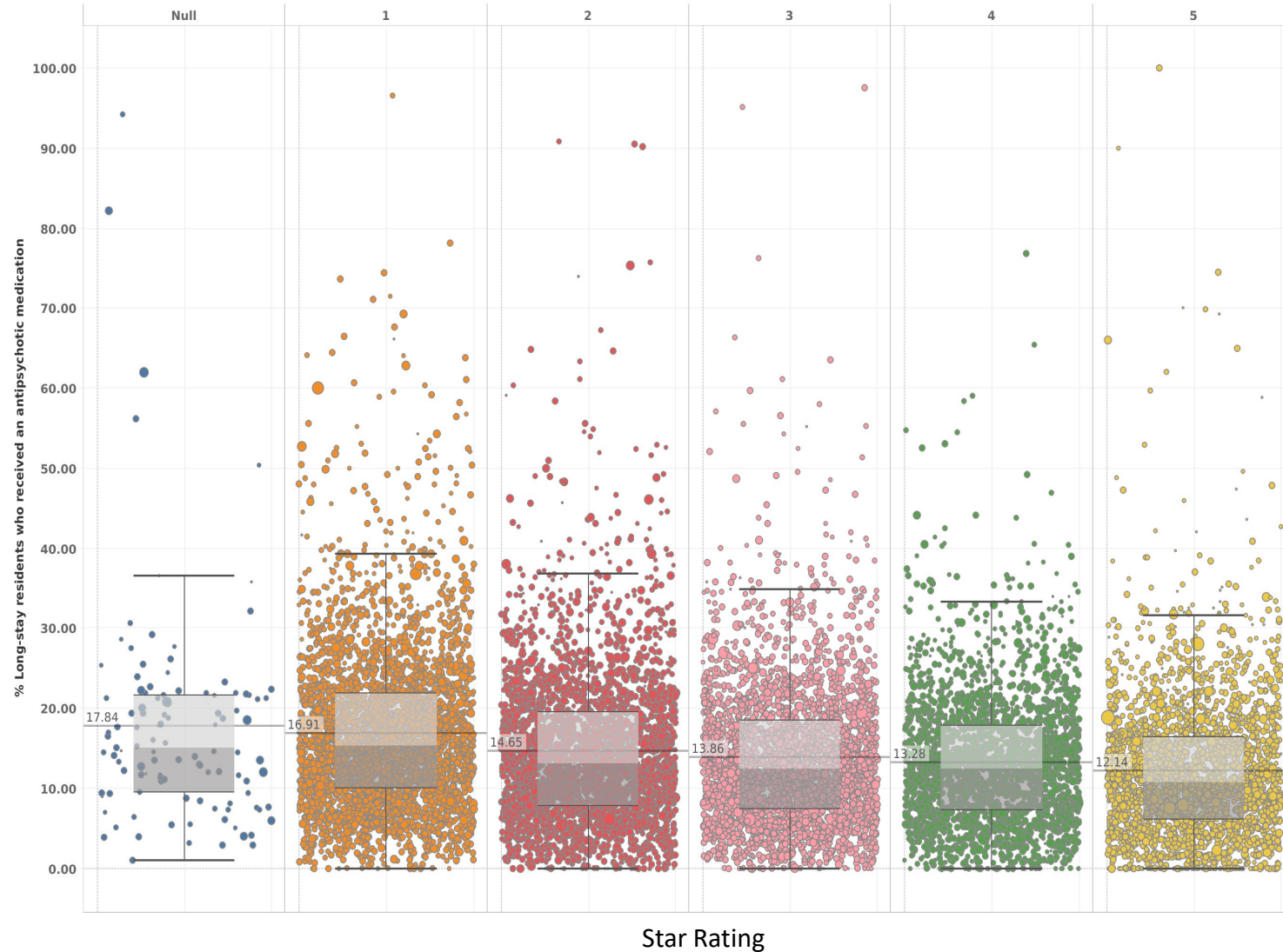


Why are the Data Important?

- High AP drugging rates can help in identifying potential care concerns.
 - ➔ Are residents being sedated for the convenience of staff?
 - ➔ Are residents, especially those with dementia, receiving appropriate care and services?
 - ➔ Is the facility providing activities that are engaging and suitable for every resident?
 - ➔ Are residents with dementia receiving appropriate care to address so-called “behavioral & psychological symptoms”?
- High use of AP drugs can be indicative of various staffing problems, including insufficient (1) nurse staffing, (2) medical director oversight, and (3) pharmacist medication review.



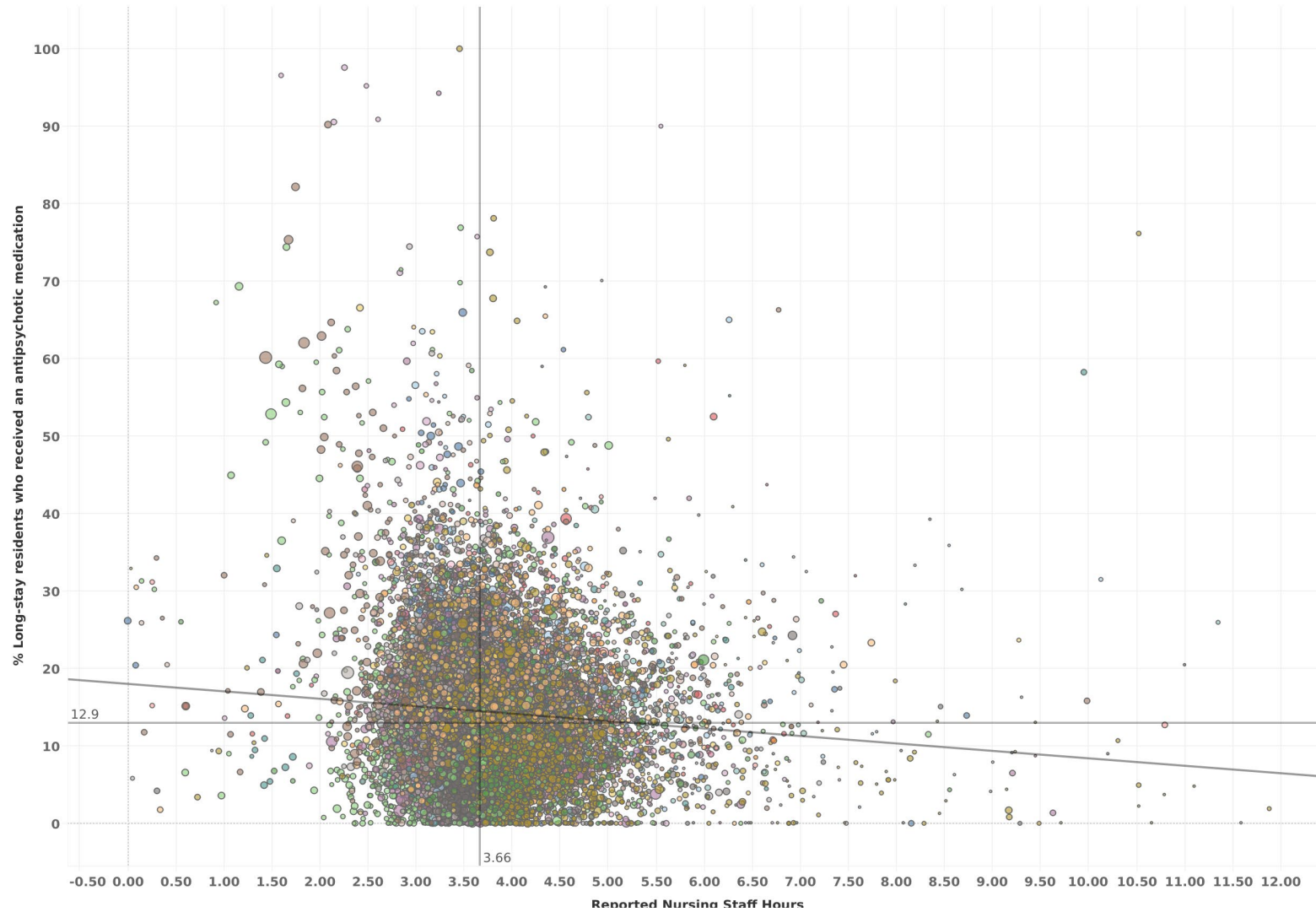
As Overall Star Rating Goes Up, AP Drugging Goes Down



5-star nursing homes have 28% higher AP drugging rates than 1-star facilities.

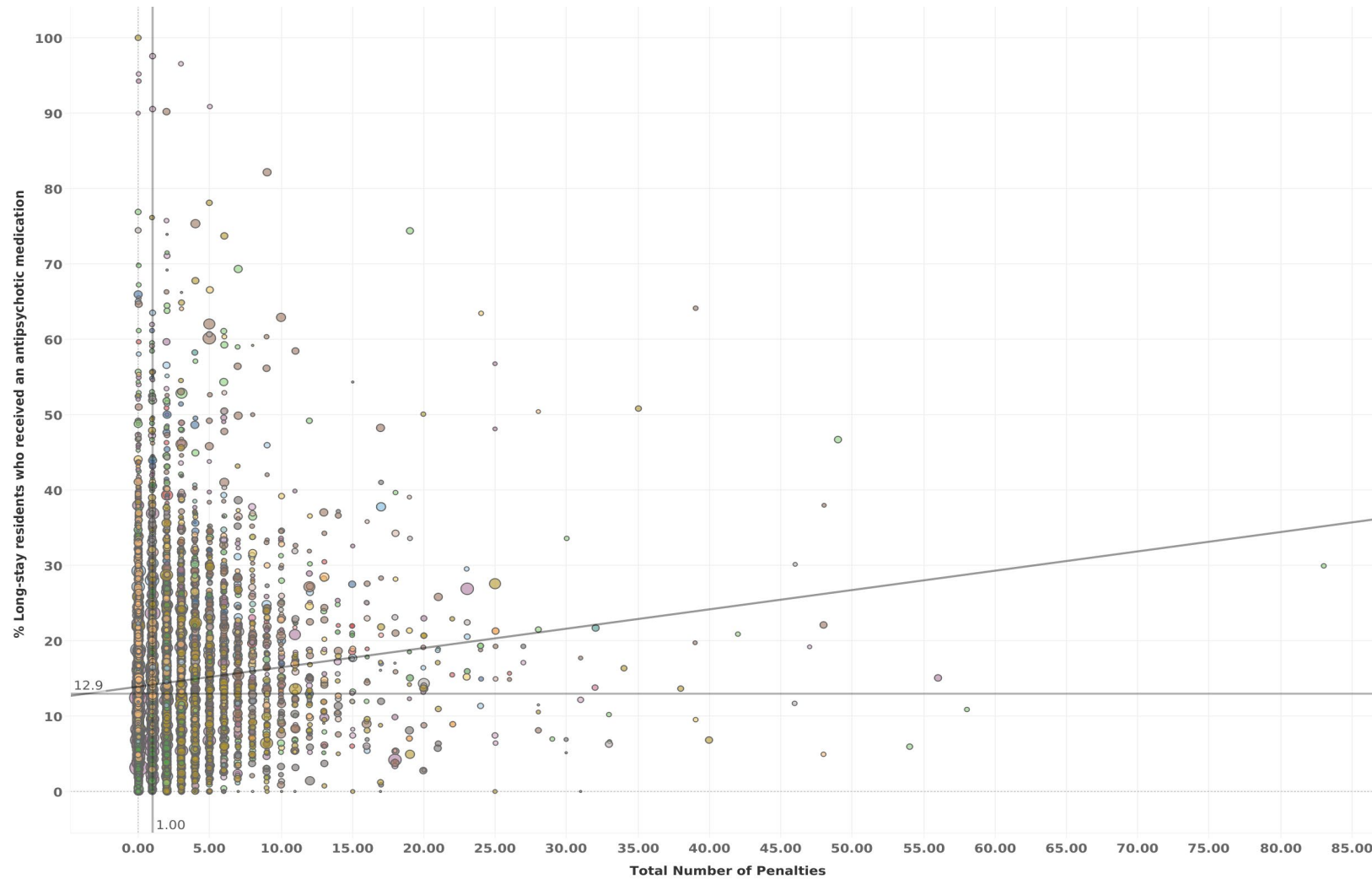


As Nursing Time Goes Up Antipsychotic Drugging Goes Down





Nursing Homes with More Penalties Have Higher AP Drugging Rates





Using the Data

- Nursing Home Care Compare provides AP drugging data in each facility's listing.
 - These data are risk-adjusted, meaning that they do not include residents who receive an AP drug and have a diagnosis of schizophrenia, Huntington's Disease, or Tourette's Syndrome.

- LTCCC provides periodic reports on nursing home AP drugging rates.
 - These data, from federal resources, include both risk-adjusted and non-risk adjusted rates.
 - Data are in a national file which can be drilled down to state, county, city, or facility-level.

Important Note: Research has shown that some nursing homes hide their actual drugging rates by giving residents a diagnosis of schizophrenia in order to chemically restrain them without it showing up in their AP drugging rates. For this reason, the non-risk-adjusted data are especially important.



Example: www.medicare.gov/care-compare

Optima Care Castle Hill

Overall rating:



CHAIN

[OPTIMA CARE](#)

LOCATION

615 23rd St

Union City, NJ 07087

PHONE NUMBER

(201) 348-0818

Save to Favorites

Ratings

Details

Location

RATINGS

Overall rating



Below average

The overall rating is based on a nursing home's performance on 3 sources: health inspections, staffing, and quality measures.

[Learn how Medicare calculates this rating](#)

Health inspections



Much below average

[View Inspection Results](#)

Staffing



Average

[View Staffing Information](#)

Quality measures



Much above average

[View Quality Measures](#)





Example: www.medicare.gov/care-compare



Long-stay quality measures ^



Much above average

The long-stay quality measures rating reflects the average level of a nursing home's performance in certain areas of care for those who stayed in a nursing home for 101 days or more, and whose typical goal is to maintain or attain their highest possible well-being while residing in the facility.

Number of hospitalizations per 1,000 long-stay resident days <i>↓ Lower numbers are better</i>	1.58 National average: 1.90 New Jersey average: 2.08
Number of outpatient emergency department visits per 1,000 long-stay resident days <i>↓ Lower numbers are better</i>	0.17 National average: 1.80 New Jersey average: 1.13
Percentage of long-stay residents who got an antipsychotic medication <i>↓ Lower percentages are better</i>	7.2% National average: 15.4% New Jersey average: 12.7% ∨
Percentage of long-stay residents experiencing one or more falls with major injury <i>↓ Lower percentages are better</i>	3.4% National average: 3.2% New Jersey average: 2.3%
Percentage of long-stay residents with pressure ulcers <i>↓ Lower percentages are better</i>	7.3% National average: 4.9% New Jersey average: 5.7% ∨



Data are available for both short-stay and long-stay residents.



LONG TERM CARE
COMMUNITY COALITION

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Who We Are Learning Center Data Center Our Work LTC in NY

Advancing Quality, Dignity, and Justice

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Each year, thousands of people attend our educational programs and access our support services.

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Webinars, podcasts, fact sheets, and other free materials to inform your advocacy for nursing home residents.

LTC In Your State
Staffing data, five-star ratings, and other important information about nursing homes in your state.

www.nursinghome411.org



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Dementia Care & Antipsychotic Drugging

Home » Nursing Home Data & Information » Dementia Care & Antipsychotic Drugging

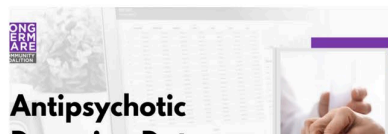


Alert: LTCCC Releases New Nursing Home Antipsychotic Drugging Data While Warning of Gaps in Federal Reporting

May 8, 2026 – The Long Term Care Community Coalition (LTCCC) today released new, facility-level data on antipsychotic (AP) drugging in U.S. nursing homes, highlighting both the continuing prevalence of antipsychotic use and disturbing limitations in [...]

Alerts, All Nursing Home Citations, Dementia Care & Antipsychotic Drugging, Nursing Home Information, States

[Read More >](#)



LTCCC Alert: Antipsychotic Drugs Administered to More Than One in Five Nursing Home Residents

VISIT OUR RESOURCE PAGE: THE DEMENTIA CARE ADVOCACY TOOLKIT

LIST OF ANTIPSYCHOTIC DRUGS

US & STATE AP DRUGGING DATA (2012-22)

APRIL 2026 LETTER IN SUPPORT OF FEDERAL AP DRUGGING MEASURE

View reports on antipsychotic drugging rates for U.S. nursing homes:

Q4 2025

Q4 2023

Q3 2023

Q2 2023

nursinghome411.org/data/ap-drugs/



Easy to use database with info on every nursing home (in compliance with federal reporting requirements).

Refine by state, county, or zip code. Search by facility name. Sort by high to low AP drugging rates.

Provider Name	State	County Name	City	Zip Code	ACTUAL Received AP Drug (Entire Resident Population)	ACTUAL Received AP Drug (Short-Stay Residents)	RISK-ADJUSTED Received AP Drug (Short-Stay Residents)	ACTUAL Received Drug (Long-Stay Residents)	RISK-ADJUSTED Received AP Drug (Long-Stay Residents)
Aase Haugen Home	IA	Winneshiek	Decorah	52101	33.87%	6.67%		42.55%	29.73%
Accura Healthcare Of Ames, Llc	IA	Story	Ames	50010					11.76%
Accura Healthcare Of Aurelia, Llc	IA	Cherokee	Aurelia	51005					12.50%
Accura Healthcare Of Bancroft	IA	Kossuth	Bancroft	50517	0.00%			0.00%	
Accura Healthcare Of Carroll	IA	Carroll	Carroll	51401	28.57%	13.33%		35.29%	28.00%
Accura Healthcare Of Cascade Llc	IA	Dubuque	Cascade	52033	26.32%	14.29%		33.33%	25.93%
Accura Healthcare Of Cherokee, Llc	IA	Cherokee	Cherokee	51012					
Accura Healthcare Of Cresco	IA	Howard	Cresco	52136					
Accura Healthcare Of Creston	IA	Union	Creston	50801					
Accura Healthcare Of Knoxville, Llc	IA	Marion	Knoxville	50138	35.00%			32.14%	24.00%
Accura Healthcare Of Lake City, Llc	IA	Calhoun	Lake City	51449					17.86%
Accura Healthcare Of Le Mars	IA	Plymouth	Le Mars	51031					18.18%
Accura Healthcare Of Marshalltown	IA	Marshall	Marshalltown	50158	48.21%	62.07%		33.33%	37.93%
Accura Healthcare Of Milford	IA	Dickinson	Milford	51351					15.63%
Accura Healthcare Of Muscatine	IA	Muscatine	Muscatine	52761	25.42%	25.00%		25.64%	12.50%
Accura Healthcare Of New Hampton	IA	Chickasaw	New Hampton	50659					20.00%
Accura Healthcare Of Newton East, Llc	IA	Jasper	Newton	50208	31.25%			30.00%	12.50%
Accura Healthcare Of Ogden, Llc	IA	Boone	Ogden	50212	40.00%			37.93%	31.03%
Accura Healthcare Of Onawa, Llc	IA	Monona	Onawa	51040					35.00%
Accura Healthcare Of Pleasantville, Llc	IA	Marion	Pleasantville	50225	58.14%			56.25%	48.15%
Accura Healthcare Of Pomeroy, Llc	IA	Calhoun	Pomeroy	50575	20.00%			21.05%	
Accura Healthcare Of Shenandoah	IA	Page	Shenandoah	51601	10.81%	11.11%		10.53%	12.50%
Accura Healthcare Of Sioux City, Llc	IA	Woodbury	Sioux City	51104	41.46%			42.86%	26.92%



Data Notes

Why is antipsychotic drugging a serious concern?	Important Data Notes:	For more info on federal requirements antipsychotic drug use and dementia c
	The data in this report are derived from two different federal datasets, as discussed below. Due to the different time frames for data collection and reporting for the sets, please note that they cover similar, but not precisely the same, timeframes.	
<p>Antipsychotic drugging in nursing homes is a critically important quality-of-care issue because these powerful medications are too often used inappropriately to control residents rather than to treat legitimate medical conditions.</p> <p>These drugs are frequently given to residents with dementia to manage behaviors such as agitation or confusion, even though safer, non-drug approaches should be tried first. Their misuse can significantly harm residents — reducing quality of life, impairing cognition, and increasing the risk of serious adverse outcomes, including falls, strokes, and even death.</p> <p>In some cases, antipsychotics are used as “chemical restraints” to make residents easier to manage, rather than to meet their medical needs. This raises serious concerns about resident rights, informed consent, and the overall standard of care in nursing homes.</p> <p>Tracking antipsychotic drugging rates at the facility level is therefore essential for transparency and accountability. These data help identify potential overuse, inform consumers and advocates, and support efforts to ensure that nursing home residents receive appropriate, person-centered care rather than unnecessary and potentially dangerous medications.</p>	<p>Columns G, H, and J are for 2025 Q4. The data were derived from the Facility-Level Minimum Data Set (MDS) Frequency files at https://data.cms.gov/quality-of-care/facility-level-minimum-data-set-frequency. They provide the ACTUAL (non-risk-adjusted) antipsychotic drugging rates for all residents by category: overall, short-stay, and long-stay.</p> <p>Data for many facilities are missing in these columns due to the CMS policy of suppressing fields in which the number is between 1-10. For example, if the total number of long-stay residents in a facility is 50 and 40 of them are not receiving antipsychotic drugs, all of the information on long-stay antipsychotic drugging will be suppressed because the number of residents receiving these drugs is between 1-10.</p> <p>Columns I and K data are for Q4 as reported on March 25, 2026 in the MDS Quality Measures files at https://data.cms.gov/provider-data/dataset/djen-97ju. These files are RISK-ADJUSTED to exclude any individual with a diagnosis of schizophrenia, Tourette’s Syndrome, or Huntington’s Disease and individuals in hospice.</p> <p>This is an important distinction because it has been found that too many facilities give their residents diagnoses with schizophrenia not because they actually have that clinical condition but, rather, to administer powerful antipsychotics to those residents without negatively impacting their “quality measure” score.</p>	<p>Dementia Care & Antipsychotic Drugging Adv https://nursinghome411.org/learn/dementia-care-toolkit/.</p>
	For more information on the risk-adjusted long-stay resident measure, see Table 2-31 of the MDS 3.0 Quality Measures USER’S MANUAL (v18.0). https://www.cms.gov/medicare/quality/nursing-home-improvement/quality-measures	



Visit www.nursinghome411.org

For all of the resources we have discussed and more...

- Webinars on resident rights and important care standards
- Abuse, Neglect, and Crime Reporting Center
- Family Empowerment Resources
- Forms & Tools for Resident-Centered Advocacy
- Assisted Living Guides
- And More!



All resources are free to use and share.

Sign-up for news & webinars at <http://nursinghome411.org/join/>.



Office of Inspector General Reports

Nursing Homes' Inappropriate Use of Antipsychotic Drugs Poses a Risk to Residents

OEI-02-23-00200, March 2026

- ▶ 40 focused nursing home inspections by CMS
- ▶ OIG found a concerning number of instances where antipsychotic drugs were inappropriately used

CMS Requirements regarding Antipsychotic Use

Nursing homes that participate in Medicare/Medicaid must meet these requirements:

- ▶ Ensuring residents remain **free from chemical restraints** imposed for the staffs' convenience
- ▶ Ensuring residents remain **free from unnecessary drugs**
 - ▶ Excessive doses, excessive duration, inadequate monitoring, & inadequate clinical indications
- ▶ Have documented **clinical rationale** for administering the medication
- ▶ Provide **gradual dose reductions** and **non-pharmacological interventions** to discontinue the use of antipsychotics in residents who were prescribed them
- ▶ Ensure **monthly reviews** of residents' medication regimens by a pharmacist
 - ▶ Pharmacists must identify irregularities and make recommendations to the residents' physician who must act on the recommendation or, if they agree, provide a rationale

▶ OIG's Findings:

- ▶ Nursing homes gave antipsychotic drugs to residents with dementia to make it easier for staff to manage their behavior
- ▶ Nursing homes did not take required steps to help protect residents who were given these drugs
- ▶ Nursing homes did not take required steps to help protect residents who were given these drugs
- ▶ Medical directors failed to prevent the inappropriate use of antipsychotic drugs
- ▶ Nursing home pharmacists failed to identify medical concerns and did not recommend dose reductions
- ▶ Inadequate nursing home policies and procedures undermined safeguards meant to protect residents

▶ OIG's Recommendations:

CMS should ...

- ▶ Further develop resources for nursing homes and transparency to reduce inappropriate use of antipsychotic drugs
- ▶ Take steps to ensure that medical directors and pharmacists do their part to reduce the use of antipsychotic drugs
- ▶ Assist nursing homes to improve their policies and procedures pertaining to antipsychotic drug use

Nursing Homes Inappropriately Diagnosed Residents with Schizophrenia to Mask the Misuse of Antipsychotic Drugs

OEI-02-23-00201, March 2026

- ▶ OIG found that nursing homes' reporting of schizophrenia diagnoses increased after the introduction of a quality measure tracking antipsychotic drug use in nursing homes
- ▶ The quality measure factors into the nursing home's star rating
- ▶ Residents with schizophrenia are not counted toward the quality measure

▶ OIG's Findings:

- ▶ Nursing homes inappropriately diagnosed residents with schizophrenia to:
 - ▶ Mask the misuse of antipsychotic drugs
 - ▶ Artificially inflate star ratings
- ▶ Medical directors made inappropriate schizophrenia diagnoses to justify prescribing antipsychotic drugs
- ▶ Nursing homes used inappropriate schizophrenia diagnoses to skirt safeguards intended to protect residents
- ▶ Nursing homes compromised residents' care by inappropriately seeking schizophrenia diagnoses

▶ OIG's Recommendations:

CMS should...

- ▶ Build on efforts to reduce inappropriate schizophrenia diagnoses in nursing homes
- ▶ Expand its use of data to monitor nursing homes' use of schizophrenia diagnoses and target oversight
- ▶ Increase efforts to ensure that nursing home residents and their families are fully informed when antipsychotic drugs are given



Advocating for Better Care

Know about their Condition, Care, and Medications

- ▶ What is their **clinical diagnosis**?
- ▶ **Progression and symptoms** of dementia
- ▶ Strategies for **individualized care**
- ▶ **Warning signs** of antipsychotic use or risk of use
- ▶ Reading a **plan of care**

Avoiding Drugs as Chemical Restraints
CONSUMER FACT SHEET

Everyone who enters a nursing home has a right to individualized, person-centered care. Some nursing facilities, however, are giving residents antipsychotic drugs, not to treat a medical diagnosis, such as Schizophrenia or Bipolar Disorder, but rather to control the resident's behavior or for the staff's convenience. When used this way, as a chemical restraint, these drugs pose special risks for older people and increase the risk of death in persons with dementia.

Signs of Someone at Risk for Chemical Restraints

When individuals, including residents with medical conditions such as dementia, are unable to express themselves using words, they express themselves through actions. For example, a resident may repeatedly moan to show they are in pain. These actions should not be dismissed. Instead, they should be evaluated to identify what the resident is trying to communicate. Other examples of behavioral communication that require further evaluation include:

- Anger, Distress, Agitation
- Screaming, Swearing, Spitting
- Hitting, Lashing out
- Confusion, Paranoia, Delusions
- Crying, Sadness, Fear
- Continuous wandering, Repetitive actions, Failure to cooperate

These actions or behaviors are signals that something is wrong!

Signs that A Resident May Have Been Chemically Restrained

Negative effects often associated with chemical restraints can also be the result of other factors such as illness or adverse effects of other drugs. However, if a resident has the following symptoms, raise questions and ask that their drug regimen be reviewed.

- Sedation (difficulty waking the resident to eat or for a visit)
- Disordered thinking, delirium, depression, hallucinations, delusions
- Distress
- Dry mouth
- Decreased appetite
- Tardive Dyskinesia (repetitive, involuntary movement of the head, tongue, and sometimes the trunk, fingers, and toes)
- Parkinsonian symptoms



Avoiding Drugs as Chemical Restraints: Consumer Fact Sheet

Pay attention to drug regimen and any changes

- ▶ Ask questions –
 - ▶ **Why** each drug was ordered
 - ▶ Potential and actual **side effects**
 - ▶ Possible **drug interactions**
 - ▶ **How** the resident has responded to each drug
 - ▶ Whether and **what efforts** have been made to reduce or eliminate its use

Non-pharmacological Interventions are Preferred, Safer

- ▶ Must be attempted **prior to** any antipsychotic drug being given
- ▶ Follow clinical guidelines:
 - ▶ Identify any **environmental triggers** for the behavior
 - ▶ Determine if symptoms are associated with **another medical condition or need**
 - ▶ Use drugs **ONLY** when other, non-pharmacological attempts to ameliorate the behaviors have failed **AND** the individual poses a threat to themselves or to others

No Drugs Should Be Administered without Informed Consent

- ▶ Residents have the right to make **informed decisions** about their care and treatment
 - ▶ Direct their own care planning
 - ▶ Understand alternatives
 - ▶ Understand risks and benefits
 - ▶ Refuse medical treatment

Ask for Assessment and Care Planning

- ▶ **Seek strategies** that do not rely on drugs
- ▶ Base care on the **resident's needs**
- ▶ Recognize that **behavior is communication**
- ▶ **Assess** medical, environmental, psychosocial causes

Empower Residents and Families

- ▶ To **ask questions** about treatments and options
- ▶ **Share information** with staff so they can better know the resident
- ▶ How to **communicate** when they face roadblocks or have concerns
- ▶ Work with the **resident and/or family council** to raise questions, concerns
- ▶ To **ask for help** from facility staff, administration, the LTC Ombudsman, survey agency, or other



Resources

Dementia Care without Drugs (Antipsychotics)

[VIEW RESOURCES](#)

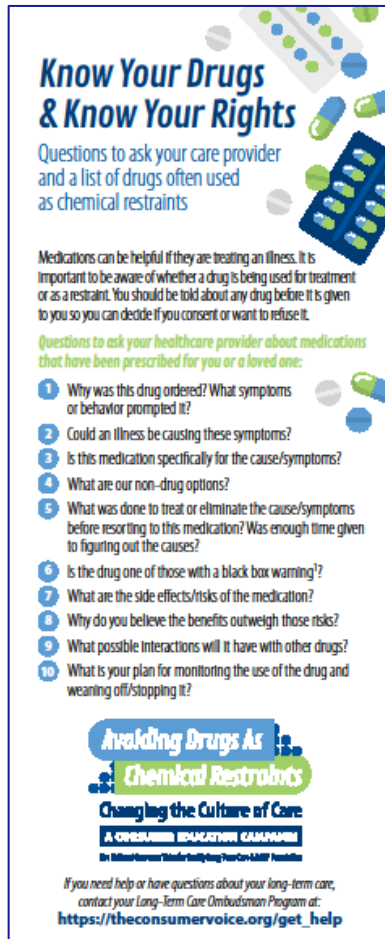
[VIEW TRAINING MATERIALS](#)



Overview

Everyone who enters a nursing home deserves quality, person-centered care. Too many residents, however, particularly those living with dementia, are being given off-label antipsychotic drugs to control their behavior instead of quality care. These drugs can have serious, life threatening side effects for older people.

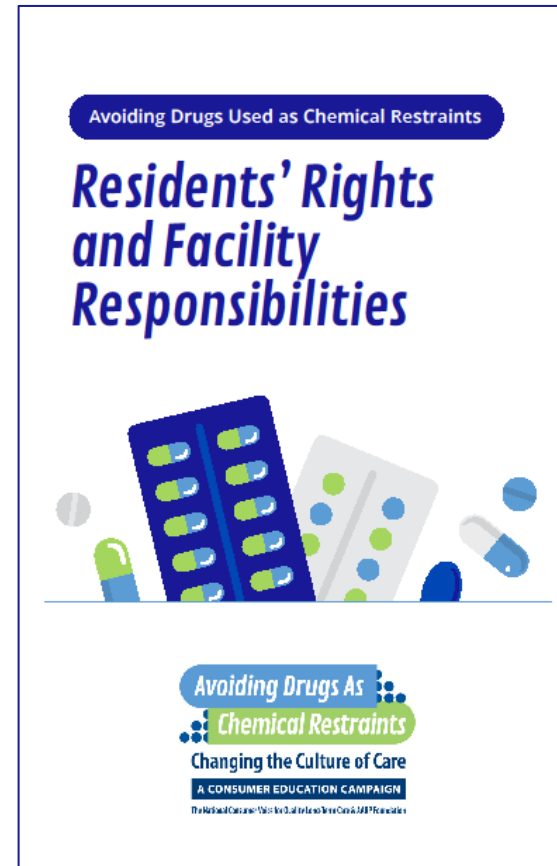
Dementia Care without Drugs webpage *Resources and training materials*



Know Your Drugs & Know Your Rights drug card

Questions to ask your care provider

List of drugs commonly used as chemical restraints



Residents' Rights and Facility Responsibilities Booklet

Educates residents about their rights and facilities about their responsibilities

“Difficult” is Not a Diagnosis

What to Do When Your Loved One is Being Pushed to Take Antipsychotic Drugs

ADVOCATE FACT SHEET

My mother recently moved into her nursing home. She has severe dementia, and I am her legal representative. Staff describe her as “difficult” because she hit a staff member and disturbs other residents. They are suggesting a new medication to control her outbursts. The staff have hinted if I say no, my mother will have to leave the nursing home.

In a nutshell

“Difficult” is not a diagnosis and it is inappropriate to label any resident this way. Actions and behaviors are a form of communication by which residents are expressing an unmet need. There are a great deal of reasons that may explain your mother’s actions, and you do not have to agree to any treatment or medication you are uncomfortable with. There are steps the nursing home should take to assess and try to address what might be causing your mother’s behavior or distress before resorting to medication, such as an antipsychotic drug, for which she may not have a clinical diagnosis. The nursing home cannot discharge your mother without any notice. There is a process. Your mother has rights.

Residents in your mother’s situation may not be able to express themselves using words. Instead, they express themselves through actions. Sometimes these actions are conveying “distress.” The response should be to identify the source of the distress and address it – not mask the symptoms with medications.

Anger, agitation, screaming, swearing, spitting, hitting, wandering, pacing, disrobing, crying, repetitive actions, unwanted sexual behavior

What are her rights?

Every person living in a nursing home has a right to quality, individualized care that meets their needs. The nursing home must provide care and services to help your mother “attain or maintain” her highest level of well-being – physically, mentally, and emotionally. This means the nursing home needs to work with your mother to determine how she can live her best life while in her facility.

You can ask the facility what’s changed that may have triggered the distress. Ask them to identify what the underlying cause might be. Could there be a medical reason? Is she in pain? Is your mother getting enough sleep? Was there an environmental change – is it too hot or cold? Is there a new roommate? Have there been changes to her routine? Has there been a change in medication? Figuring out the cause of the distress or need is necessary for finding an appropriate solution. A new assessment may be necessary.

Nursing homes must assess each resident and create a plan of care that spells out what care and services the person will receive to meet their needs, preferences, and goals. Care plans need to be re-evaluated every three months, or when there is a change in condition, to determine if something should be added or deleted from the plan. If your mother shows distress, or the facility suggests a new medication to control your mother’s behavior, request a care planning conference.

For more information about resident rights view the fact sheet [Nursing Home Residents’ Rights](#).

“Difficult” is Not a Diagnosis: What to Do When You’re Loved One is Being Pushed to Take Antipsychotic Drugs

Difficult is Not a Diagnosis

Advocacy strategies for getting good care

Avoiding Drugs as Chemical Restraints

CONSUMER FACT SHEET

Everyone who enters a nursing home has a right to individualized, person-centered care. Some nursing facilities, however, are giving residents antipsychotic drugs, not to treat a medical diagnosis, such as Schizophrenia or Bipolar Disorder, but rather to control the resident’s behavior or for the staff’s convenience. When used this way, as a chemical restraint, these drugs pose special risks for older people and increase the risk of death in persons with dementia.

Signs of Someone at Risk for Chemical Restraints

When individuals, including residents with medical conditions such as dementia, are unable to express themselves using words, they express themselves through actions. For example, a resident may repeatedly moan to show they are in pain. These actions should not be dismissed. Instead, they should be evaluated to identify what the resident is trying to communicate. Other examples of behavioral communication that require further evaluation include:

- Anger, Distress, Agitation
- Screaming, Swearing, Spitting
- Hitting, Lashing out
- Confusion, Paranoia, Delusions
- Crying, Sadness, Fear
- Continuous wandering, Repetitive actions, Failure to cooperate

} **These actions or behaviors are signals that something is wrong!**

Signs that A Resident May Have Been Chemically Restrained

Negative effects often associated with chemical restraints can also be the result of other factors such as illness or adverse effects of other drugs. However, if a resident has the following symptoms, raise questions and ask that their drug regimen be reviewed.

- Sedation (difficulty waking the resident to eat or for a visit)
- Disordered thinking, delirium, depression, hallucinations, delusions
- Distress
- Dry mouth
- Decreased appetite
- Tardive Dyskinesia (repetitive, involuntary movement of the head, tongue, and sometimes the trunk, fingers, and toes)
- Parkinsonian symptoms



Avoiding Drugs as Chemical Restraints: Consumer Fact Sheet

Avoiding Drugs Used as Chemical Restraints

Warning signs, rights, and strategies



Questions?



Updates and News

Meet us in St. Louis!

- ▶ **Consumer Voice Annual Conference is in St. Louis, Missouri!**
- ▶ **September 28-October 1, 2026**, at the Hyatt Regency St. Louis at the Arch.
- ▶ Offered in-person and virtually.
- ▶ Take a sneak peak at the [Agenda!](#)
- ▶ [Registration is open!](#)
- ▶ Connect with advocates from across the country to learn, network, and exchange ideas on long-term care issues, including current trends, best practices, and advocacy opportunities!

Dignity Served Daily *Bringing Resident Voices to the Table*

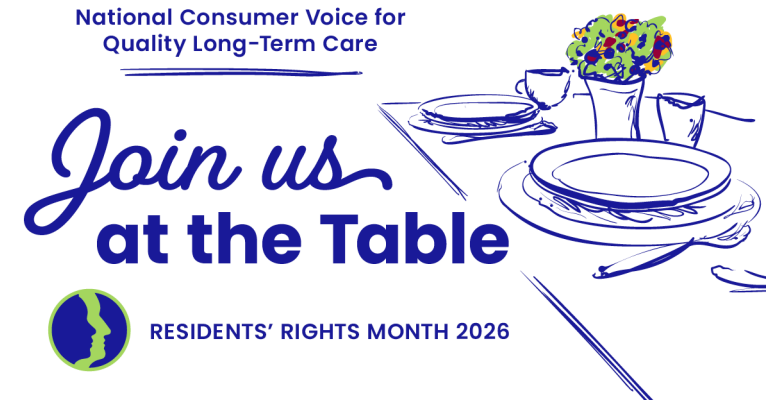
September 28 – October 1, 2026
St. Louis, Missouri



National Consumer Voice for Quality Long-Term Care
2026 ANNUAL CONFERENCE

October is Residents' Rights Month

- ▶ Annual event honoring individuals in long-term care facilities.
- ▶ **2026 Theme: "Join Us at the Table"**
 - ▶ Highlights the importance of food and mealtime. The theme connects health, identity, culture, and community, and encourages residents to share preferences and experiences.
- ▶ **Resident's Voice Challenge**
 - ▶ Residents submit creative works (recipes, stories, artwork, videos) that focus on food traditions and personal experiences.
 - ▶ Consumer Voice will create a recipe book featuring resident submissions including recipes, traditions, and meaningful memories.
 - ▶ Encourage residents to submit favorite recipes via the [collection form](#).
- ▶ **Learn more:** <https://theconsumervoice.org/2026-residents-rights-month/>



▶ **NEW** NORC Website and Resources Launch!

Wednesday, July 29, 2:00 – 3:00pm ET



▶ [Register!](#)

Connect with us!



The National
CONSUMER VOICE
for Quality Long-Term Care

- 🌐 theconsumervoice.org
- ✉ info@theconsumervoice.org
- f The National Consumer Voice for Quality Long-Term Care
- 🐦 @ConsumerVoices



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

- 🌐 ltcombudsman.org
- ✉ ombudcenter@theconsumervoice.org
- f The National LTC Ombudsman Resource Center
- 🐦 @LTCombudcenter