

While you wait...

Virtual Meeting Tips

- Put your **questions in the Q&A** at the bottom of your Zoom screen
- Use the chat feature at the bottom of your Zoom screen for **comments** and conversation
- If you are having technical issues, please let us know in the chat and we will do our best to assist you



New at NursingHome411

- LTC Journal: Spring 2022
- Q4 2021 Staffing Data
- LTCCC's Comments to CMS on Minimum Staffing Standard
- LTCCC Policy Brief: Nursing Home Transparency
- LTCCC Memo: Informed Consent
- Elder Justice "No Harm" Newsletter (Vol. 4, Issue 3)

For materials from today's webinar, visit nursinghome411.org/webinar-ap-drugs/

The Long Term Care Community Coalition

- **LTCCC** is a nonprofit, nonpartisan organization dedicated to improving care & quality of life for the elderly & adult disabled in long-term care (LTC).
- **What we do:**
 - Policy research & analysis;
 - Systems advocacy;
 - Public education;
 - Home to two local LTC Ombudsman Programs.



www.nursinghome411.org

Today's Webinar:



LTCCC WEBINAR:

A Campaign Sedated: Dangerous Antipsychotic Drugging Persists Despite Federal Initiative

Tuesday, June 21, 2022 | 1-2PM ET

Register: bit.ly/ap-drugs-2022



LTCCC's **Richard Mollot** and CANHR's **Tony Chicotel** discuss the dangers of antipsychotic (AP) drugging in nursing homes, the failures of a federal campaign to reduce APs, and what needs to be done to improve dementia care.

**For materials from today's webinar, visit
nursinghome411.org/webinar-ap-drugs/**

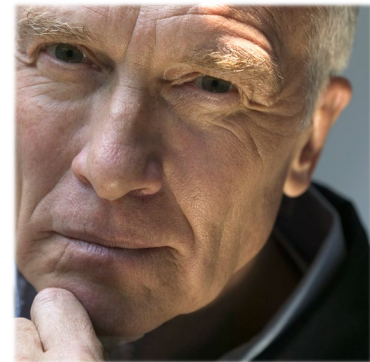
What Will We Be Talking About TODAY?

- The problem: Widespread overuse of dangerous and powerful drugs to sedate residents.
- The rules: Federal standards that are in place to...
 1. Protect nursing home residents from inappropriate drugging and
 2. Ensure good dementia care.
- Principles of least drugging / good dementia care.
- The national campaign to address this persistent problem.
 1. The successes and failures of the campaign – and why they matter and
 2. Where do we go from here?



The Problem

- Approximately one in five (20%) nursing home residents are being given powerful antipsychotic (AP) medications.
- In fact, only about 2% of the population is **ever** diagnosed with a psychotic condition recognized by CMS as potentially appropriate for these drugs.
- Too often, these drugs are administered to residents to sedate them, for the convenience of staff.
- This is a problem because...
 - AP medications are highly potent drugs that are indicated to treat specific conditions, such as schizophrenia.
 - **AP drugs are not clinically indicated to treat dementia or so-called “dementia behaviors.”**
 - AP drugs commonly have **serious side-effects**, including: movement disorders, falls, hip fractures, and strokes.
 - AP drugs stupefy residents and can seriously **exacerbate functional and cognitive limitations**.
 - **Antipsychotic drugs are NOT EFFECTIVE for more than a short period of time in addressing “behavioral symptoms of dementia.”**



The Problem

- The Food & Drug Administration (FDA) “Black Box” warning states, “Elderly patients with dementia-related psychosis treated with atypical antipsychotic drugs are at an increased risk of death....”
- **Despite the FDA’s ‘black box’ warnings, they are frequently used as a form of chemical restraint, sedating residents so that their behaviors *and* the underlying causes of those behaviors are left unaddressed by staff.**

**Black Box
Warning**



**WARNING: INCREASED MORTALITY IN ELDERLY PATIENTS
WITH DEMENTIA-RELATED PSYCHOSIS**
See full prescribing information for complete boxed warning.
Elderly patients with dementia-related psychosis treated with
antipsychotic drugs are at an increased risk of death. RISPERDAL[®] is
not approved for use in patients with dementia-related psychosis. (5.1)

The Nursing Home Reform Law

- The 1987 Nursing Home Reform Law (aka OBRA 87) requires that **every** nursing home resident is provided the care and quality of life sufficient for them to attain and maintain their highest practicable **physical, emotional** and **social** well-being.
- This is what we pay for.
- This is what providers agree to provide.
- This is what every resident deserves.



The Reform Law & Antipsychotic Drugging

- The 1987 Nursing Home 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.**

The Law: Residents' Rights

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

CONSUMER FACTSHEET: ANTIPSYCHOTIC DRUGGING

This factsheet discusses two of the principal antipsychotic drugging standards and how you can use them to advocate for your resident. This page provides the major points from the federal regulations. The next page provides tips on what YOU can do to advocate for better care.

STANDARD 1: PHARMACY SERVICES¹ [42 CFR §483.45]

- 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 [dispense as needed] 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.

STANDARD 2: BEHAVIORAL HEALTH SERVICES² [42 CFR §483.40]

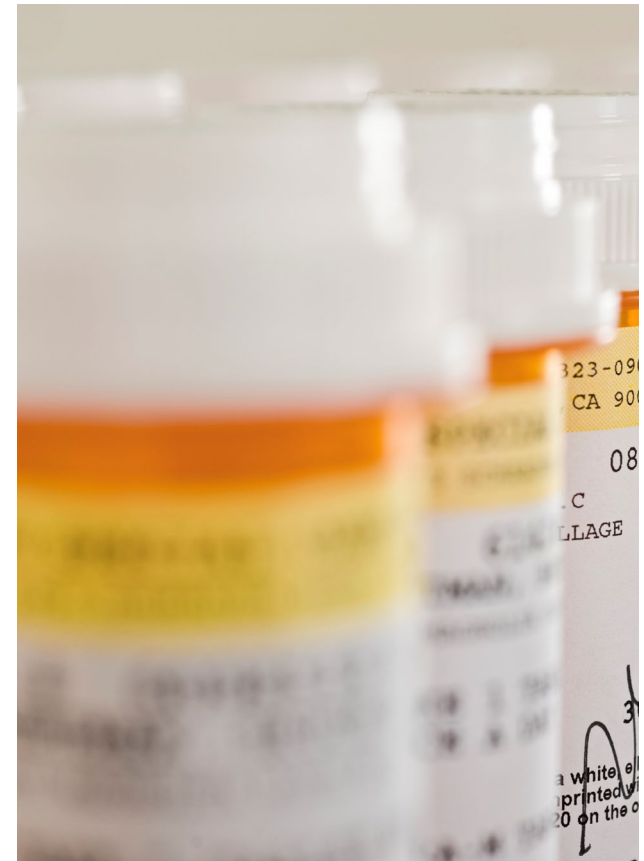
- Each resident must receive and the facility must provide the necessary behavioral health care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care. Behavioral health encompasses a resident's whole emotional and mental well-being....
- The facility must have sufficient staff who provide direct services to residents with the appropriate competencies and skills sets to provide nursing and related services to assure resident safety and attain or maintain the highest practicable physical, mental and psychosocial wellbeing of each resident, as determined by resident assessments and individual plans of care....
These competencies and skills sets include, but are not limited to, knowledge of and appropriate training and supervision for:
 - (1) Caring for residents with mental and psychosocial disorders... and
 - (2) Implementing non-pharmacological interventions.
- Based on the comprehensive assessment of a resident, the facility must ensure that.... A resident who displays or is diagnosed with dementia, receives the appropriate treatment and services to attain or maintain his or her highest practicable physical, mental, and psychosocial well-being.

- **Freedom from Chemical Restraints:** It is against the law to give medications that do not benefit the resident, such as convenience of staff.
- **Informed Decision-Making:** Residents have the right to be informed about the risks and benefits of any medication.
- **Right to Refuse:** Residents have the right to refuse medication.

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

Antipsychotics since 1987: A Timeline

1987	Nursing Home Reform Law proscribes chemical restraints & requires resident-centered care.
Late 1990s	AP drug use increases as second-generation APs are marketed (illegally & inappropriately) as safe to use on residents w/dementia.
2005	FDA imposes black box warning for second-generation AP medications for elderly patients with dementia. This warning was added for first-generation APs in 2008.
2011	Inspector General Levinson identifies rampant inappropriate use of AP drugs in nursing homes, says residents, families, tax-payers should be "outraged."... Nursing home resident advocates meet with the acting administrator of CMS. He agrees to take action.
2012	CMS launches federal campaign to reduce antipsychotic drugging, promising swift, substantive change to protect residents.
2014	LTCCC study finds modest decrease in AP drugging, but that they are still administered to one in five (20%) residents.
2016	New federal standards strengthen protections against inappropriate drugging, including requirement of monthly pharmacist review of resident medications.
2017	New federal requirements for nursing home surveys include review of resident medications and sufficiency of facility staffing.
2020	AP drug rates increase as COVID-19 pandemic hits US nursing homes.
2021	LTCCC study finds virtually no enforcement of either drugging or staffing standards; NY Times investigation finds significant rise in schizophrenia diagnoses, leading to increased inappropriate AP drugging.
2022	CMS announces plans to identify problematic diagnoses and refocus efforts to reduce inappropriate use of APs.



The Partnership

Press release

CMS ANNOUNCES PARTNERSHIP TO IMPROVE DEMENTIA CARE IN NURSING HOMES

May 30, 2012 | Nursing facilities, Psychiatric

- In May 2012, CMS announced partnership with providers, caregivers, and patients to reduce AP drugs.
 - *Context: in 2011, Inspector General report found widespread failure to comply with federal regulations aimed at preventing overmedication.*
- National goal of reducing use of antipsychotic drugs in nursing home residents by 15 percent by the end of 2012.
 - In Q2 2012, more than a quarter of residents received APs, according to MDS 3.0 data (non-risk adjusted).
 - “Almost 40 percent of nursing home patients with signs of dementia were receiving antipsychotic drugs at some point in 2010, even though there was no diagnosis of psychosis.”

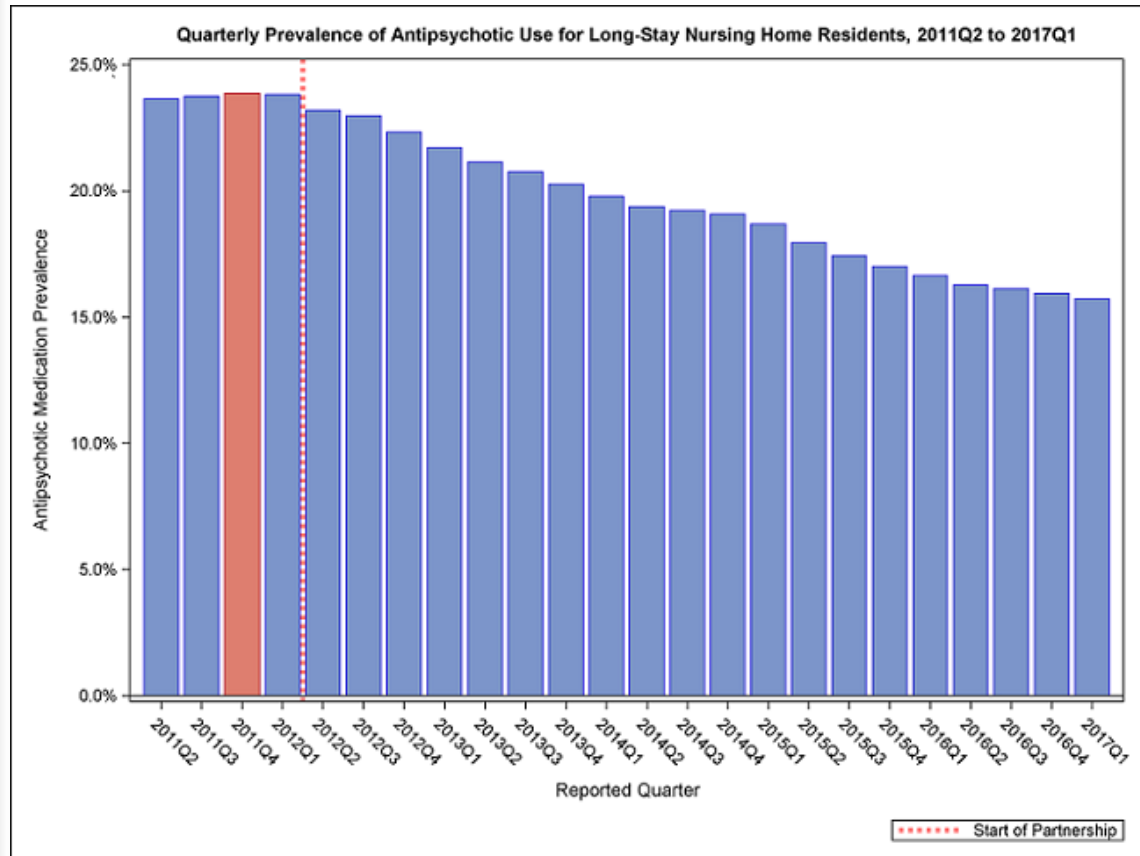


The Partnership

Modest success at the beginning...

- From Q4 2011 to Q1 2017, AP use (risk-adjusted) dropped 34.1%.
- This is an average of just 6.5% reduction per year.
- Close to 16% of residents (risk-adjusted) are still getting AP drugs.
- 20% (non-risk-adjusted) are still getting AP drugs.

Important disclaimer: Risk-adjusted excludes schizophrenia, Tourette's syndrome and Huntington's disease. More on this later...

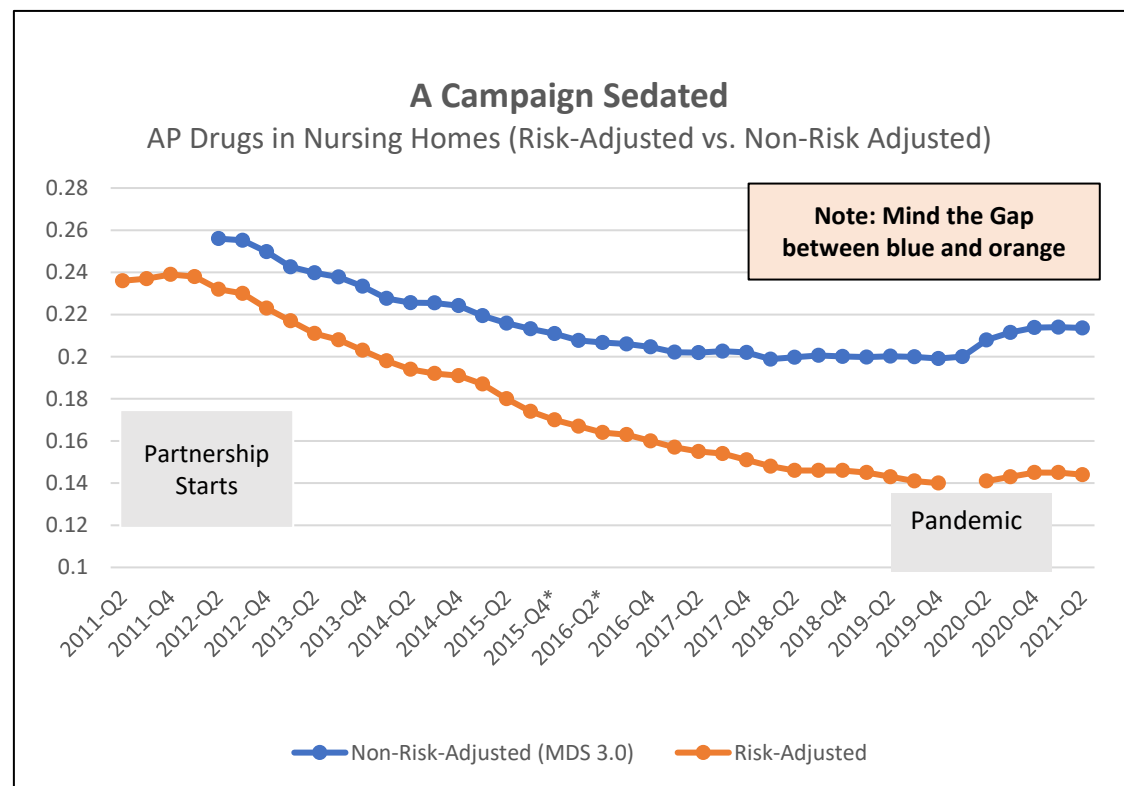


Source: <https://www.cms.gov/newsroom/fact-sheets/data-show-national-partnership-improve-dementia-care-achieves-goals-reduce-unnecessary-antipsychotic> (CMS 2017)

A Campaign Sedated...

• In Q2 2021, AP drugs were administered to 21% of nursing homes residents.

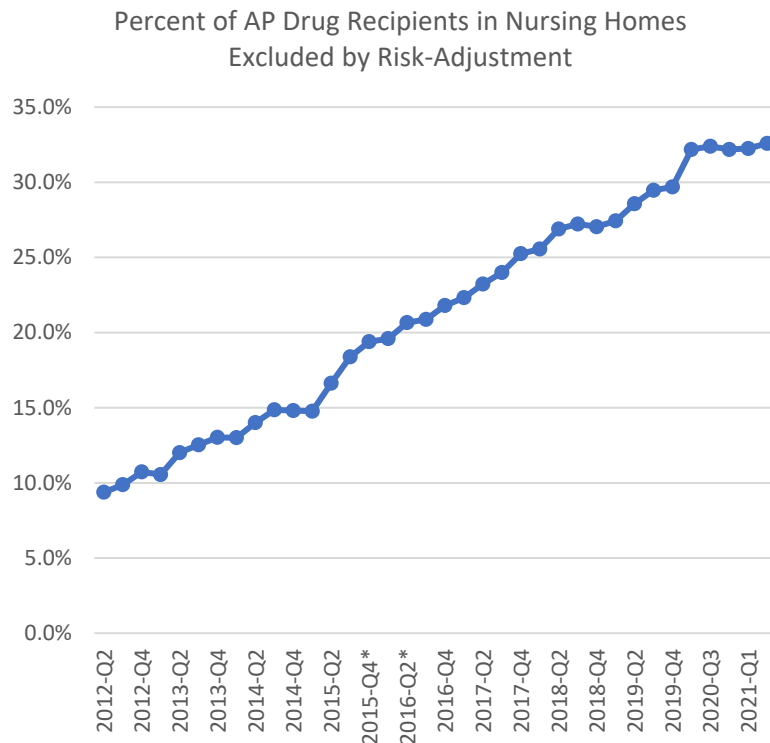
- Roughly 10x (!) the rate of the population that will ever have a diagnosis qualifying for potentially appropriate AP use.
 - Risk-adjusted AP drug rates plateau after 2017, *increase slightly* in pandemic.
 - Non-risk adjusted AP drug rates plateau, then *increase significantly* in pandemic.
- Note the widening gap between blue (non-risk-adjusted) and orange (risk-adjusted).



Sources: Non-risk-adjusted data via MDS 3.0 Frequency Reports: <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/Minimum-Data-Set-3-0-Frequency-Report>. Risk-adjusted data via CMS.

*Quarterly risk-adjusted data from 2015-Q4 to 2016-Q2 are estimates based on [graph from 2017 CMS report](#). Data from other quarters are based on numbers included in data tables.

Risk-Adjustments on the Rise



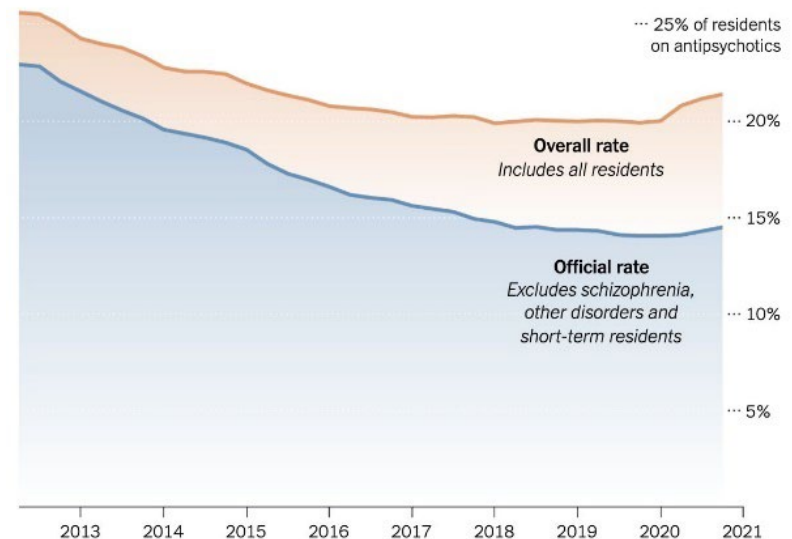
- **Risk-adjustment:** Patients diagnosed with schizophrenia, Huntington's Disease, or Tourette's Syndrome excluded from risk-adjusted AP drug rates.
- In 2012, **less than 10%** of residents receiving APs were excluded by risk-adjustment.
- In 2021, **nearly a third (32.6%)** of residents receiving APs were excluded by risk-adjustment.
 - Put differently: Nearly 1 in 3 residents receiving APs are excluded from risk-adjusted data. It used to be 1 in 10...

Schizophrenia diagnoses on the rise

- CMS data are **risk-adjusted**. Those data **exclude** individuals with Schizophrenia, Tourette's Syndrome and Huntington's Disease.
 - Nationwide, phony Schizophrenia diagnoses (NY Times).
 - *Note: Schizophrenia diagnoses higher in black residents (JAGS/NY Times).*
- **Rise in schizophrenia diagnoses driving discrepancy in risk-adjusted and non-risk-adjusted data.**

A Growing Gap in Antipsychotic Drug Reporting

Official rates of antipsychotic drug use by nursing homes exclude residents diagnosed with schizophrenia. Unfounded diagnoses contributed to a decline in recent years, which appears less sharp when all residents are included.



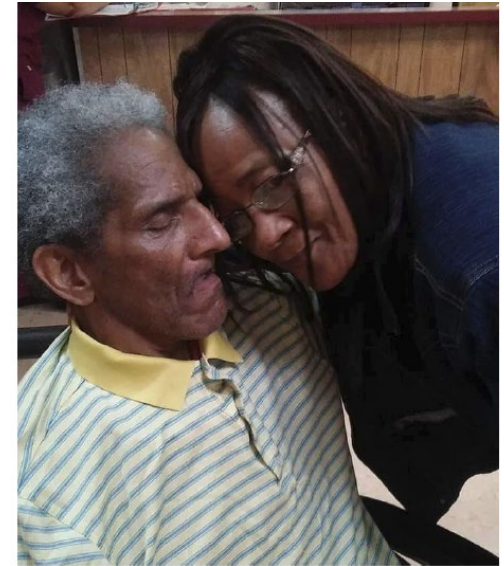
By The New York Times | Sources: National Partnership to Improve Dementia Care in Nursing Homes; Centers for Medicare & Medicaid Services MDS 3.0 Frequency Reports

The Residents Left Behind

“At least 21 percent of nursing home residents are on antipsychotic drugs, a Times investigation found.” – NYT, 2021

- One of those residents: David Blakeney, 63, nursing home resident living with severe dementia
- A doctor diagnosed Mr. Blakeney, with no evidence, of schizophrenia
- With Mr. Blakeney’s new diagnosis, his AP prescription disappeared from his nursing home’s public record
- “Eight months following his admission with a long list of ailments – and after round-the-clock sedation, devastating weight loss, pneumonia and severe bedsores that required one of his feet to be amputated – Mr. Blakeney was dead.”

- *The New York Times*, “Phony Diagnoses Hide High Rates of Drugging at Nursing Homes



The Blakeney's at Dundee Manor in January 2017, five months before Mr. Blakeney's death. Courtesy of Yvonne Blakeney

PHYSICIAN TELEPHONE ORDER

DATE RECEIVED: 1/25/17

PHYSICIAN: Dr. [Signature]

REASON FOR ORDER: [Handwritten notes]

PLACED IN THE FOLLOWING APPROPRIATE AUDIT BOX

Recorded on MD Order Sheet | Pharmacy | Medication Order | Nurse Note | Care Plan

ORIGINAL COPY-Physician Please Sign and Return Immediately

PHYSICIAN TELEPHONE ORDER

Name of Facility: Dundee Manor

Family Name: Blakeney

First Name: David

Address: B'ville

Admission Number: 8054

Attending Physician: Smith

DATE RECEIVED: 10-17-16

PHYSICIAN: [Signature]

REASON FOR ORDER: Add DX of schizophrenia for use of Haldol

PHYSICIAN TELEPHONE ORDER

PLACED IN THE FOLLOWING APPROPRIATE AUDIT BOX

Recorded on MD Order Sheet | Pharmacy | Medication Order | Nurse Note | Care Plan

ORIGINAL COPY-Physician Please Sign and Return Immediately

The doctor's telephone order adding Mr. Blakeney's schizophrenia diagnosis at Dundee Manor. Yvonne Blakeney

The Residents Left Behind

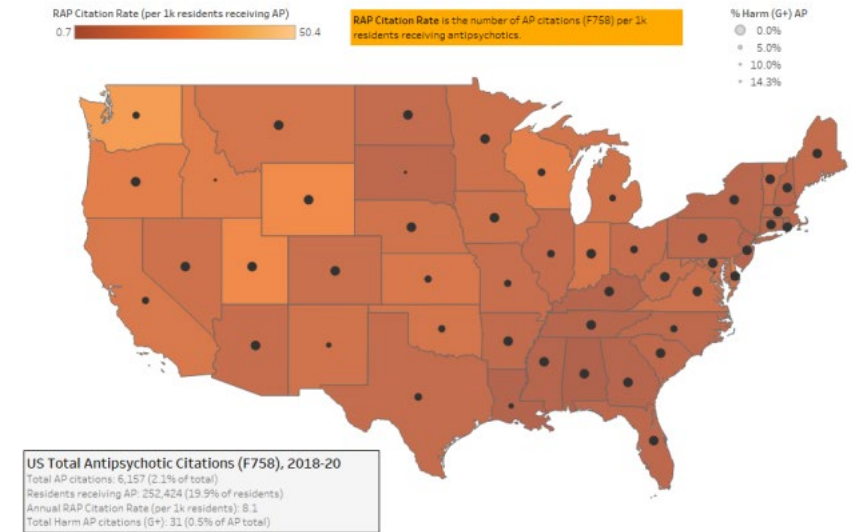
“In an average week, nursing facilities in the United States administer antipsychotic drugs to over 179,000 people who do not have diagnoses for which the drugs are approved.” – Human Rights Watch, 2018

- “Too many times I’m given too many pills... [Until they wear off], I can’t even talk. I have a thick tongue when they do that. I ask them not to [give me the antipsychotic drugs]. When I say that, they threaten to remove me from the [nursing] home. They get me so I can’t think. I don’t want anything to make me change the person I am.”
 - Walter L., 81, from *Human Rights Watch*, “They Want Docile”
- “It used to be like a death prison here. We cut our antipsychotics in half in six months. Half our residents were on antipsychotics. Only 10 percent of our residents have a mental illness.”
 - Director of Nursing, Kansas facility, from *Human Rights Watch*, “They Want Docile”
- “I had no idea, not at all, that the drugs were dangerous. I had no idea... I’m guessing most people have no idea.”
 - Daughter of a nursing home resident consenting to antipsychotic drugs for her mother, from *Human Rights Watch*, “They Want Docile”

Overprescribed, Underenforced

- F758 (Free from Unnecessary Psychotropic Meds)
 - 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.
- Only 6,157 AP citations recorded from 2018-20.
 - 8.1 AP citations per year for every 1,000 residents reported to be receiving antipsychotics.
 - 31 total AP citations (0.5%) categorized as harm (G+). In other words, even when surveyors substantiate inappropriate resident drugging, **99.5% of the time they find no resident harm.**
- Despite years of training for both state surveyors and nursing home staff on the dangers of AP drugs...
 - Widespread AP drugging persists.
 - State surveyors are disinclined to hold nursing home accountable for it.

RAP Antipsychotic Citation Rate and Severity by State (2018-20)



<https://nursinghome411.org/survey-data-report/>

Looking to the Future: White House reforms includes addressing antipsychotic drugging and low staffing



Reinforce Safeguards against Unnecessary Medications and Treatments.

Thanks to CMS' National Partnership to Improve Dementia Care in Nursing Homes, the nation has seen a dramatic decrease in the use of antipsychotic drugs in nursing homes in recent years. However, inappropriate diagnoses and prescribing still occur at too many nursing homes. **CMS will launch a new effort to identify problematic diagnoses and refocus efforts to continue to bring down the inappropriate use of antipsychotic medications.**

Part II:
Tony Chicotel, CANHR

My Kids



Preview

- What I'm talking about:
 - the campaign (what we've done)
 - the principles of good dementia care (what we should be doing).
- What I'm not talking about:
 - Why psych drugs are often the wrong way
 - Public Policy

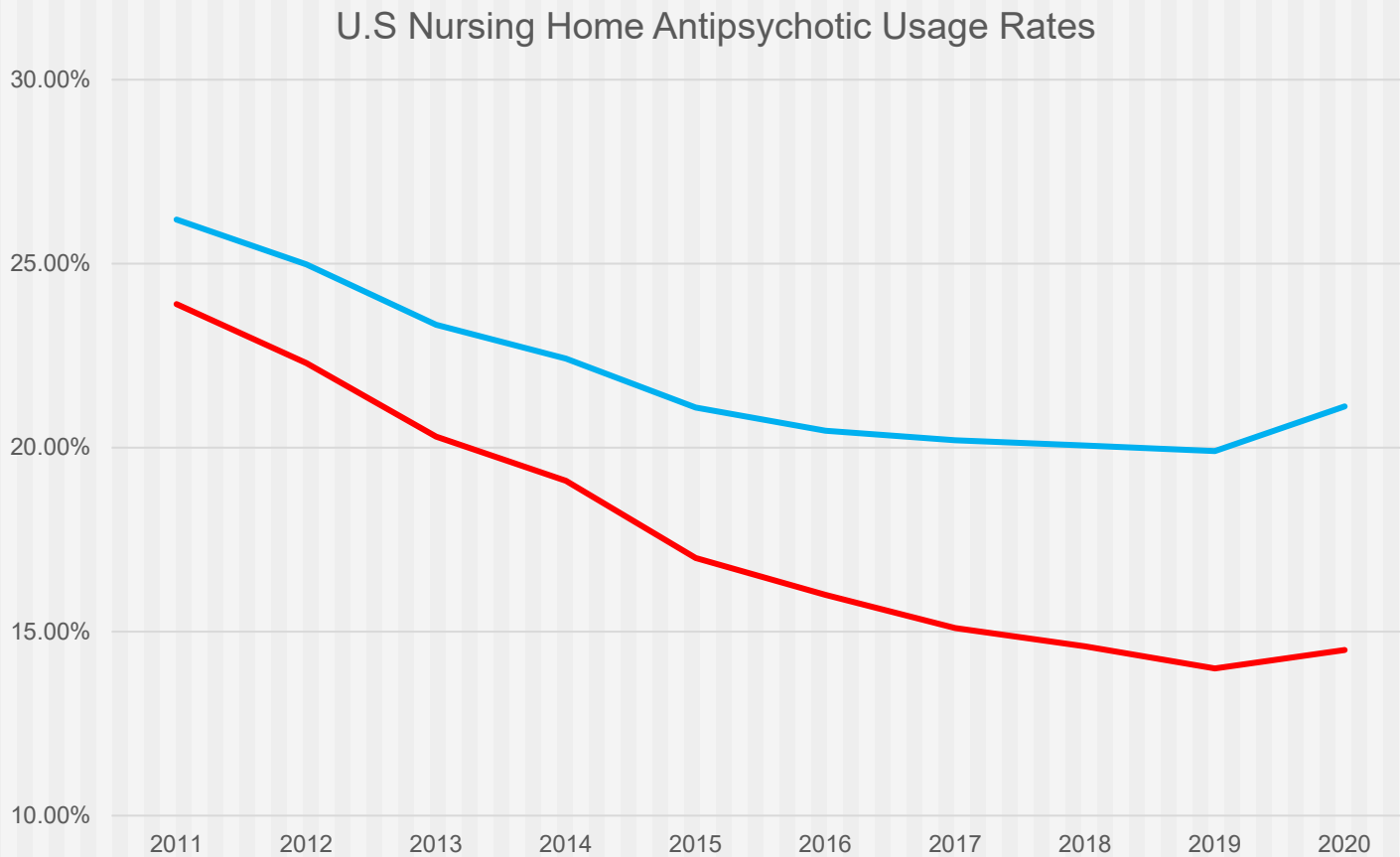
The Campaign - History

- 2006 WSJ story
- 2010 CANHR website, campaign
- 2011 OIG report, Berwick's dad, AHCA offers to reduce AP use by 15% voluntarily
- 2012 National PARTNERSHIP - framed as a joint effort, education-focused, data elements, enforcement secondary

The Campaign – Results

- A lot of work, some improvement, a lot of missed opportunities
- A focus on disputed data

The Data – How We Tell the Story



The Least Drugging Approach

- Dementia changes the way one thinks and communicates but not the way one feels. Emotions still in tact.
- Behavior as communication, often of unmet need
- BPSD should be OTD

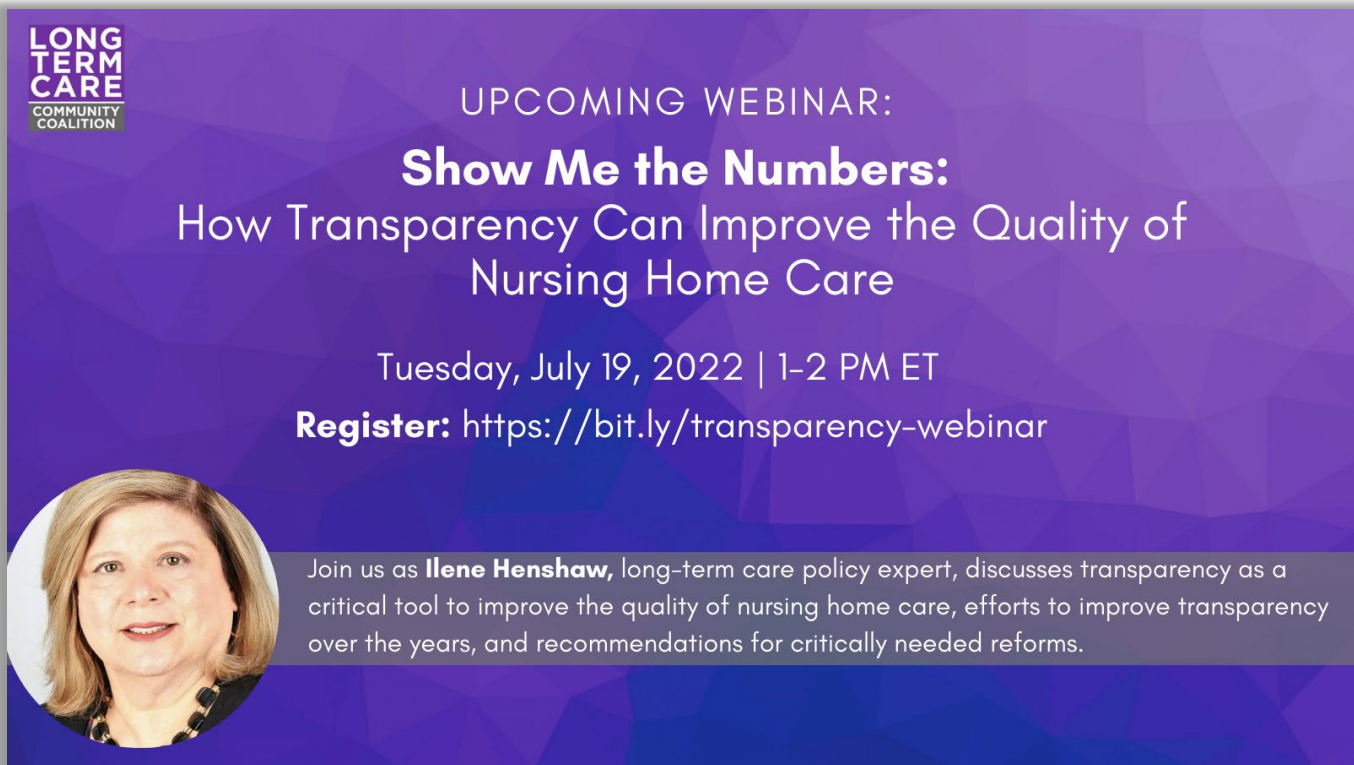
The Least Drugging Approach

- Unmet need is how we think of caring for babies but for older adults we don't. We should.
- How do we make them feel good, safe, whole, and loved?
- It's not rocket science. But it requires thought. Calling a prescriber doesn't.



LTCCC's July Webinar

- **Show Me the Numbers: How Transparency Can Improve Quality of Nursing Home Care**
 - Tuesday, July 19, 1pm ET
 - Presenter: Ilene Henshaw
 - Register: <https://bit.ly/transparency-webinar>




LONG TERM CARE
COMMUNITY COALITION

UPCOMING WEBINAR:

Show Me the Numbers:
How Transparency Can Improve the Quality of
Nursing Home Care

Tuesday, July 19, 2022 | 1-2 PM ET

Register: <https://bit.ly/transparency-webinar>



Join us as **Ilene Henshaw**, long-term care policy expert, discusses transparency as a critical tool to improve the quality of nursing home care, efforts to improve transparency over the years, and recommendations for critically needed reforms.

Head to NursingHome411...



- For materials from today's webinar, visit <https://nursinghome411.org/webinar-ap-drugs>
- For LTCCC's antipsychotic data, visit <https://nursinghome411.org/data/ap-drugs/>
- To register for LTCCC's July webinar, visit <https://bit.ly/transparency-webinar>

Thank You For Joining Us Today!

**For updates & invites to future programs:
www.nursinghome411.org/join/.**

LTC Ombudsmen: Look out for an email confirming your attendance of this program on Thursday.

