



Treating Behavioral and Psychological Symptoms of Dementia Without Drugs

Avoiding the Misuse of Antipsychotic Drugs

This training toolkit is a product of the Avoiding Drugs as Chemical Restraints Consumer Education Campaign of the National Consumer Voice for Quality Long-Term Care and AARP Foundation.

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Behavioral and Psychological Symptoms of Dementia (BPSD)

Evaluating and Treating

BPSD Symptoms

Affects quality of life of patients and caregivers

Physical/Verbal	Psychological
Restlessness	Depression/anxiety
Wandering/Pacing	Apathy
Hitting/scratching/biting	Sleep disturbances
Throwing things	Psychosis – hallucinations, delusions
Social inappropriateness	
Physical sexual advances	
Screaming/cursing	
Temper outbursts	

Assessment of BPSD

Behavioral and Psychological Symptoms of Dementia



- ▶ Assess patients with dementia for the type, frequency, severity, pattern, and timing of symptoms
 - ▶ Why?
 - ▶ Help in identifying possible contributors to symptoms
 - ▶ Establish baseline level and pattern of symptoms to assess later treatment response
 - ▶ How?
 - ▶ Obtain via face-to-face evaluation, review medical records, and/or history (including from family and friends)

**American Psychological Association*

Common Triggers to Behaviors

- ▶ Hunger, fatigue, pain, too hot, or too cold
- ▶ Recent medication change or change in response to the medications (e.g., increased symptoms, side effects, drug interactions)
- ▶ Physical issues (e.g., infection)
- ▶ Discomfort or distress related to bowel or bladder issues (e.g., constipation, incontinence)
- ▶ Under-stimulation or over-stimulation (e.g., boredom, loneliness, noise, clutter or other environmental factors)



Other Common Triggers

- ▶ Vision or hearing deficits
- ▶ Confronted with cognitively challenging situations or demands
- ▶ Being assisted with or rushed to complete tasks (e.g., bathing, dressing, or other activities of daily living)
- ▶ Feeling a loss of privacy, modesty, or other loss of control
- ▶ Sensing frustration, anxiety, or other emotional distress of caregivers

Evaluating Symptoms



Identify the underlying causes of distress, agitation, or aggression

Pain	Delirium	Unmet needs
Medications	Sleep issues	Environmental triggers
Sensory deficits, e.g., difficulty seeing or hearing	Cognitive, language deficits, e.g., difficulty communicating	Depression, anxiety, apathy, psychosis

Antipsychotic Drugs Used Off-Label

- ▶ Despite known dangers, antipsychotic drugs are commonly prescribed to elderly nursing facility residents for uses not approved by the FDA:
 - ▶ To control unwanted or challenging behavior caused by dementia;
 - ▶ To avoid increased staffing and training needs for non-pharmacological interventions to modify these behaviors



Dangers of Antipsychotic Drugs

- ▶ Increased mortality when used for dementia-related psychosis
 - ▶ FDA Black Box Warning – most serious type of warning that appears on the package insert
 - ▶ There is no FDA-approved psychotropic drug treatment for dementia-related behaviors
- ▶ Increased risk of stroke, heart attack, death
- ▶ Should not be used routinely and should be regularly assessed
- ▶ Potential risks and benefits must be assessed by the clinician and discussed with the patient (or representative)

Drug name	Generic name
Risperdal	Risperidone
Seroquel	Quetiapine Fumarate
Geodon	Ziprasidone Hydrochloride; Ziprasidone Mesylate
Abilify	Aripiprazole
Invega	Paliperidone; Paliperidone Pamate
Haldol	Haloperidol Decanoate; Haloperidol Lactate; Haloperidol
Moban	Molindone Hydrochloride
Navane	Thithixene
Orap	Pimozide
Symbyax	Fluoxetine Hydrochloride; Olanzapine
Clozaril	Clozapine
Fazaclo	Clozapine



Antipsychotic Drugs with Black Box Warnings

Impact of Psychotropic Drugs

Affect mental activity, emotion, and behavior (e.g., antipsychotics, antidepressants, mood stabilizers)

- ▶ Side effects can be harmful; diminish quality of life
- ▶ Results in increased vulnerability to infections
- ▶ Cause excessive sedation, lethargy, dizziness, unsteadiness which can lead to increased falls and injuries, increased risk of bed sores
- ▶ Parkinsonism (tremors and rigidity), body restlessness
- ▶ Reduced well-being, loss of appetite, social withdrawal
- ▶ Accelerated cognitive decline

Failure to Monitor after Drugs are Administered

Many facilities administer the drugs and do not monitor the consequences:

Antipsychotic Drugs can cause:

- Drowsiness
- Lethargy
- Dizziness
- Confusion
- Restlessness
- Loss of appetite
- Dysphasia
- Tremors
- Rigidity
- Increased vulnerability to infections



Leading to:

- Falls
- Weight loss
- Dehydration
- Shuffling
- Incontinence
- Pressure Ulcers
- Difficulty communicating
- Social withdrawal
- Isolation
- Death

Nonpharmacological Interventions are Preferred, Safer

Clinical Guidelines*

- ▶ Assess the scope and severity of the behavior
- ▶ Identify any environmental triggers for the behavior
- ▶ Determine if behavioral symptoms are associated with another medical condition (e.g., pain, constipation, de-hydration)
- ▶ 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

*AMDA, *The Society for Post-Acute and Long-Term Care*

Nonpharmacological Strategies are Preferred, Safer

- ▶ Shown to reduce agitation and anxiety in dementia
- ▶ Techniques should be individualized
- ▶ Incorporates:
 - ▶ Behavioral interventions
 - ▶ Caregiver education and training
 - ▶ Sensory techniques

Behavioral Interventions

Nonpharmacological Strategies

- ▶ Avoid, remove triggers – noise, light, temperature, etc
- ▶ Ensure a consistent routine and environment
- ▶ Avoid sudden changes
- ▶ Determine/anticipate unmet needs (e.g., pain, thirst, hunger)
- ▶ Recognize that language and memory deficits can hinder communications of what is needed
- ▶ Provide person-centered care

Caregiver Education and Training

Nonpharmacological Strategies

- ▶ Knowing the individual – likes, dislikes, preferences, routines, history
- ▶ Caring for individuals with dementia, cognitive impairments
- ▶ Communication skills training
- ▶ Provide calm, reassuring communication when patients seem anxious
- ▶ Use redirection and distraction techniques

Sensory Techniques

Nonpharmacological Strategies

- ▶ Aromatherapy
- ▶ Music therapy
- ▶ Massage and touch therapy
- ▶ Exercise
- ▶ Pet therapy



Other Strategies

Nonpharmacological Strategies

- ▶ Monitor closely
- ▶ Stop non-essential medications
- ▶ Reduce psychiatric symptoms
- ▶ Provide cognitive structure/emotional support
- ▶ Maintain function

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Rights and Responsibilities

Federal Rules and Requirements

Residents' Rights



Federal Requirements

- ▶ Treated with respect and dignity and care for each resident in a manner and in an environment that promotes maintenance or enhancement of quality of life, recognizing each resident's individuality
- ▶ Free from physical or chemical restraints
- ▶ Informed, consent, or refuse treatment
- ▶ Choose a physician
- ▶ Free from unnecessary drugs – i.e., excessive dose, excessive duration, without adequate monitoring, without adequate clinical indications for its use, presence of adverse consequences indicating dose should be reduced or discontinued
- ▶ Informed of, and participate in, treatment, including the right to request, refuse, discontinue treatment

Facility Responsibilities



Federal Requirements

- ▶ Sufficient staff to assure resident safety and provide services for each resident to reach or maintain their highest level of well-being
- ▶ Assure staff have the skills and training around:
 - ▶ Caring for residents with mental and psychosocial disorders
 - ▶ Implementing non-pharmacological interventions
 - ▶ Dementia management
 - ▶ Abuse prevention
- ▶ Assessment and care planning
- ▶ Medical Regimen Review, at least monthly, but more frequently, if necessary

Requirements Specific to Antipsychotic Use

Federal Requirements



- ▶ Residents who have not used psychotropic drugs are not given the drug unless necessary to treat a specific condition as diagnosed and documented in the clinical record
- ▶ Gradual dose reduction and behavioral interventions (unless clinically contraindicated)
- ▶ PRN (as needed) psychotropic drug use limited to 14 days
 - ▶ Unless evaluation by the attending or prescribing physician for appropriateness; and documentation of the rationale in the medical record

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Advocacy Strategies

Use Data in Your Advocacy



- ▶ Ombudsman Complaint Data (NORS)
 - ▶ Chemical Restraints
 - ▶ Care Issues
 - ▶ Staffing
 - ▶ Discharge
- ▶ Care Compare – www.medicare.gov/care-compare/

Care Compare – Facility data

The screenshot displays the Medicare Care Compare website for a nursing home. The browser address bar shows the URL: <https://www.medicare.gov/care-compare/details/nursing-home/395067?city=Scranton&state=PA&zipcode=18504>. The page has three tabs: "Ratings", "Details", and "Location", with "Ratings" selected. The "RATINGS" section includes:

- Overall rating:** 1 star (1 filled, 4 empty), labeled "Much below average". A green arrow points to this section. Text: "The overall rating is based on a nursing home's performance on 3 sources: health inspections, staffing, and quality measures." Link: [Learn how Medicare calculates this rating](#).
- Health inspections:** 1 star (1 filled, 4 empty), labeled "Much below average". Button: [View Inspection Results](#).
- Staffing:** 2 stars (2 filled, 3 empty), labeled "Below average". Button: [View Staffing Information](#).
- Quality measures:** 4 stars (4 filled, 1 empty), labeled "Above average". Button: [View Quality Measures](#).

The "DETAILS" section includes:

- COVID-19 vaccination and booster rates:** Text: "The percent of residents and staff who are vaccinated for COVID-19 in the nursing home, as well as the percent of residents and staff with completed vaccinations who received boosters, along with the state and national rates." Button: [View Vaccination Rates](#).

A vertical "Feedback" button is located on the right side of the page.

Green Ridge Care Center

Quality measures

Print

- [Learn more about quality measures](#)
- [Find out why these short-stay measures are important](#)
- [Find out why these long-stay measures are important](#)
- [Get current data collection period](#)

Quality measures rating



Short-stay quality measures



Long-stay quality measures



Feedback

medicare.gov/care-compare/details/nursing-home/395067?city=Scranton&state=PA&zipcode=18504&measure=nursing-home-quality-of-care

2021 Consumer Voi...

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 ↓ Lower numbers are better	0.80 National average: 1.40 Pennsylvania average: 1.24
Number of outpatient emergency department visits per 1,000 long-stay resident days ↓ Lower numbers are better	0.56 National average: 0.86 Pennsylvania average: 0.58
Percentage of long-stay residents who got an antipsychotic medication ↓ Lower percentages are better	15.9% National average: 14.5% Pennsylvania average: 15.5%
Percentage of long-stay residents experiencing one or more falls with major injury ↓ Lower percentages are better	5.3% National average: 3.4% Pennsylvania average: 3.4%
Percentage of long-stay high-risk residents with pressure ulcers ↓ Lower percentages are better	2.4% National average: 8.2% Pennsylvania average: 7.7%

Feedback

What to Look For:

- ▶ Lower rated facilities (i.e., 1 star, 2 star)
- ▶ Staffing problems
- ▶ Behavioral health issues
- ▶ Onsite observations
- ▶ Complaints

Overall Star Rating	% Residents Receiving APs
1	26.51%
2	22.90%
3	21.01%
4	19.24%
5	16.17%

Facility Advocacy

- ▶ Talk about the data – antipsychotic use, schizophrenia diagnoses
- ▶ Ask questions
 - ▶ How does the facility support residents' mental health needs?
- ▶ Share information and resources – such as:
 - ▶ CMS's Hand in Hand Training Series - <https://qsep.cms.gov/pubs/HandinHand.aspx>

Individual Resident Advocacy

- ▶ Assessment and care plan
- ▶ Non-pharmacological strategies
- ▶ Informed consent
- ▶ Medication review
- ▶ Mental health assessment

▶ Additional Advocacy Strategies

- ▶ Engage, inform residents, families, Councils
- ▶ Licensing Agency – referrals, information sharing
- ▶ Partners – coordination, referrals, education
 - ▶ Disability Rights
 - ▶ Legal Services
 - ▶ Consumer Advocates
 - ▶ Medicaid Fraud Control Units

Avoiding Drugs As

Chemical Restraints

Changing the Culture of Care

A CONSUMER EDUCATION CAMPAIGN

The National Consumer Voice for Quality Long-Term Care & AARP Foundation

<https://theconsumervoice.org/stop-chemical-restraints>

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

A CONSUMER EDUCATION PODCAST

PURSuing QUALITY LONG-TERM CARE

Know Your Drugs & Know Your Rights

Questions to ask your care provider and a list of drugs often used as chemical restraints

Medications can be helpful if they are treating an illness. It is important to be aware of whether a drug is being used for treatment or as a restraint. You should be told about any drug before it is given to you so you can decide if you consent or want to refuse it.

Questions to ask your healthcare provider about medications that have been prescribed for you or a loved one:

- 1 Why was this drug ordered? What symptoms or behavior prompted it?
- 2 Could an illness be causing these symptoms?
- 3 Is this medication specifically for the cause/symptoms?
- 4 What are our non-drug options?
- 5 What was done to treat or eliminate the cause/symptoms before resorting to this medication? Was enough time given to figuring out the causes?
- 6 Is the drug one of those with a black box warning?
- 7 What are the side effects/risks of the medication?
- 8 Why do you believe the benefits outweigh those risks?
- 9 What possible interactions will it have with other drugs?
- 10 What is your plan for monitoring the use of the drug and weaning off/stopping it?

Avoiding Drugs As Chemical Restraints

Changing the Culture of Care

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If you need help or have questions about your long-term care, contact your Long-Term Care Ombudsman Program at:
https://theconsumervoice.org/get_help



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Questions?

Speaker Contact Information

- ▶ Name | email
- ▶ Name | email
- ▶ Name | email