# Guidance on Inappropriate Use of Antipsychotics:
## Older Adults and People with Intellectual and Developmental Disabilities in Community Settings

## WHAT IS THE ISSUE?

Behavioral manifestations of conditions such as dementia and IDD are common, at times escalating to the point of agitation and aggression that can be dangerous for both the person as well as caregivers.[1,2] Although approaches to care aimed at behavioral modification should be first-line for challenging behaviors, older adults and people with disabilities are often prescribed sedating medications such as antipsychotics as a way to manage disruptive behavior. These prescribing practices can expose these individuals to significant risk and should be used only when clinically indicated.

### WHO IS THIS GUIDANCE FOR?

This guidance is intended primarily for physicians and other prescribers as well as support staff, administrators, and caregivers working with people with dementia and persons with intellectual and developmental disabilities (IDD) in community settings.

The example of inappropriate antipsychotics use in elderly people living in nursing homes is illustrative. Both first and second generation antipsychotics are associated with increased stroke risk and increased overall mortality in people with dementia.[3] In 2008, the Food and Drug Administration (FDA) issued an advisory and black box warning that "the treatment of behavioral disorders in elderly patients with dementia with … antipsychotic medications is associated with increased mortality."[4] Subsequently, the Department of Health and Human Services (HHS) Office of the Inspector General (OIG) issued a report that found 14 percent of elderly nursing home residents had Medicare claims for second generation antipsychotic drugs, and 88 percent of those were prescribed for dementia despite the FDA's warnings.[5]

Following the OIG's recommendations, the Centers for Medicare & Medicaid Services (CMS) created the National Partnership to Improve Dementia Care in Nursing Homes to promote public reporting, state-based coalitions, research, training, and revised surveyor guidance.[6] In 2015, the Government Accountability Office (GAO) reported that "among Medicare Part D enrollees with dementia living outside of a nursing home [in 2012], about 14 percent were prescribed an antipsychotic," compared to about one third of older adults with dementia who had spent more than 100 days in a nursing home.[7] The GAO report recommended continued focus on reducing antipsychotic use for people living with dementia in nursing home settings, and to expand the focus to other settings. Attention to this issue has been a focus of consumer advocacy groups[8] and for the HHS National Alzheimer's Project Act's Advisory Council.[9]

In the case of IDD, in one study nearly 40 percent of all adults with IDD were dispensed an antipsychotic medication, and 56 percent of a sub-cohort of group home residents were taking antipsychotic medications.[10] Furthermore, 29 percent of those prescribed an antipsychotic medication did not have a documented psychiatric diagnosis, despite the lack of evidence that antipsychotics confer a clinical benefit to people with IDD.[10] These trends are even more concerning for children and youth on long-term antipsychotic treatment given that they are physically and emotionally more vulnerable to the adverse effects.[11]

SAMHSA Substance Abuse and Mental Health Services Administration · CMS Centers for Medicare & Medicaid Services · HRSA Health Resources & Services Administration · ACL Administration for Community Living

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## PRESCRIBERS AFFECTED

Affected prescribers are physicians and other prescribers caring for Medicare and Medicaid beneficiaries with dementia or IDD. Older adults and people with disabilities often receive health care services through Medicare, Medicaid, or both. While the majority of efforts through CMS's National Partnership have focused on antipsychotic use in nursing homes, many people living with dementia or IDD are in community settings such as their own homes, group homes, assisted living facilities, and other congregate settings.

People living in the community often have their medications prescribed by primary care providers who are required to regularly review and complete medication lists, in part to reduce polypharmacy and discontinue inappropriate prescriptions. A subset of Medicaid beneficiaries enrolled in home and community based services (HCBS) programs are required to have a person-centered plan to address individual needs, including any challenging behaviors associated with dementia or other cognitive impairment.[12] Overall, therapeutic approaches, including medication utilization in community settings, are less monitored and regulated than in nursing homes and hospital settings and therefore need special attention to ensure appropriate prescribing practices.

## PRINCIPLES OF CARE

Given the complexities of working with older adults and people with disabilities, the following general principles should be considered in developing and implementing an actionable care plan for each individual.

### ASSESSMENT

A person-centered planning process is needed to begin the assessment process. Behavioral symptoms should be carefully assessed based on the underlying disorder(s), disease stage, and possible contributing factors such as medication regimen, time of day, staff or caregivers, environmental stressors and unmet needs.

It is critical to distinguish behavioral manifestations of conditions like dementia and IDD from other potential causes. Dementia and IDD frequently co-occur with both mental and physical comorbidities. Many physical conditions manifest as delirium and should be promptly identified. Causes can include infection, electrolyte disturbances, constipation, pain, sleep disturbance, sensory impairment, and polypharmacy. If a medical cause of the altered mental status or behavioral disturbance is identified, the underlying condition should be treated and mental status monitored carefully.[13]

If no medical etiology is identified and the behavioral symptoms are recurrent, then psychiatric comorbidities should also be considered. Symptoms of depression, anxiety and psychosis are possible in both dementia and IDD and should be addressed on a case by case basis. Before suspected psychiatric conditions are treated pharmacologically, any environmental stressors should be identified and addressed using strategies such as positive interventions, environmental modifications, and careful transition from or to a particular setting. If environmental approaches are insufficient, antidepressants can be considered for certain older adults and persons with IDD as treatment for depressive and anxiety disorders, in combination with appropriate non-pharmacologic approaches to care.[13]

If an individual is determined to have active psychosis (such as auditory or visual hallucinations, or delusions including paranoia), the treatment strategy will vary depending on the underlying condition(s).[13] Older adults with a history of primary psychotic disorders are treated differently than those who manifest psychosis as part of a late-life disorder, given that the balance between benefit and risk of antipsychotic treatment are different with chronic mental illnesses than new onset psychosis due to dementia.[14] In the case of IDD, co-occurring psychotic disorders are more common and therefore may require antipsychotic prescriptions when psychosis has been detected.[10]

## PRINCIPLES OF CARE (cont.)

### GOALS OF CARE

All aspects of a person-centered care plan—including both pharmacologic and non-pharmacologic approaches to care—should always be regularly assessed and reviewed. Informed consent is necessary and should include discussion of the care plan with the person or a legal representative. It is important to include individuals themselves, people close to them, and their caregivers in these conversations from the outset and incorporate person-centered principles across all areas of care (e.g., communication preferences, use of technology, work or volunteer status, finances, housing, and advanced care planning).[15]

### CARE PLAN: Non-pharmacologic approaches to care for behavioral disturbances

If an alternate diagnosis (e.g. delirium, mental disorder) has been excluded as the cause of a behavioral disturbance, then non-pharmacologic treatments should be considered as first-line interventions. Each behavior should be clearly identified and documented in order to make a relevant treatment plan, and positive behavioral management strategies should be tried before considering medications. Even if medications are added, behavior management interventions should continue.

### Workforce Training

The Geriatrics Workforce Enhancement Program (GWEP), administered by the Health Resources and Services Administration (HRSA), provides support to develop a health care workforce that maximizes patient and family engagement to improve health outcomes in older adults by integrating geriatrics and primary care. Each grant recipient is required to have strong reciprocal partnerships between academia, primary care delivery sites and systems, and community-based organizations. GWEP grant recipients educate and train inter-professional teams of health professions students, faculty, practitioners, direct care workers, patients, families, and caregivers on appropriate use of antipsychotic medications in older adults living in the community. In addition, HRSA developed a resource for caregivers that describes additional helpful strategies, titled, "Training Curriculum: Alzheimer's Disease and Related Dementias."[19]

There are many interventions that can have significant benefit for people experiencing behavioral symptoms.[16] For example, the American Association of Geriatric Psychiatry's principles of care for people with dementia recommends day-to-day living be structured to maximize a person's current abilities and function.[15] Strategies include modifications such as helping individuals maintain a routine schedule, avoiding demanding or challenging tasks, focusing on creating a positive environment, and leaning about and providing opportunities to engage in activities that are important to the person.

A range of techniques can yield significant improvements for each individual. Principles of applied behavior analysis include evaluating behavior using the Antecedent-Behavior-Consequence (ABC) Model, avoiding or reducing experiences that trigger behaviors, and employing strategies that promote alternative behaviors such as positive phrasing, praising desired behaviors, relaxation techniques, distraction, and tangible reinforcers.[17] Results of other approaches remain inconclusive as to behavioral benefits, such as music therapy, aroma therapy, massage, and multisensory stimulation.[18]

Clinicians should review previous behaviors and responses to interventions whenever possible, including via behavioral charting review and caregiver report.[13] Care should be tailored to the individual with a person-centered, multidisciplinary approach that addresses psychosocial aspects of care.

## PRINCIPLES OF CARE (cont.)

### CARE PLAN: Pharmacologic treatment for severe behavioral disturbances

Medications are only indicated as a last resort if aggression, agitation or psychotic symptoms cause severe distress or an immediate risk of harm to the individual or others.[20]

#### *Dementia:*

The American Psychiatric Association released a comprehensive "Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia" in 2016, which reviews the evidence for antipsychotics in this population.[13] In general, it describes the following principles:

Principles for Prescribing Antipsychotics for People with Dementia with Behavioral Disturbances

- Antipsychotic medications should be avoided when possible;
- If indicated, dosage should be started as low as possible with modest increases only when necessary;
- Second generation antipsychotics are preferable over first generation antipsychotics due to more favorable side effect profiles;
- Medications should be discontinued if no clinical benefit is observed;
- Discontinuation may need to be considered for those who experience side effects even if there is improvement in behavioral symptoms; and
- Taper should be attempted for ALL patients within 4 months of treatment with close monitoring.

As a general principle, the side effect profile of antipsychotics should be aligned with patient risk. For example, second generation antipsychotics may cause metabolic syndrome and weight gain, which should be avoided in an overweight person with diabetes.[21] In the case of Parkinson's disease and Lewy Body Dementia, in particular, hallucinations are common, yet these individuals are at particularly high risk of side effects of antipsychotics, which should therefore be avoided whenever possible.[22]

#### *Intellectual and Developmental Disabilities:*

*IDD:* For people with IDD who do not have psychotic disorders (e.g. Autism Spectrum Disorder, Down Syndrome), the use of antipsychotics has scant evidence of efficacy, has been shown to cause significant side effects, and should therefore be avoided.[10] If a person with IDD has had challenging behaviors without psychosis and has been maintained on antipsychotic medications, taper and discontinuation of such medications should be attempted periodically.[23] Tapering of antipsychotic doses should be monitored carefully and guided by each individual's symptoms and behaviors. A tapering schedule of decreasing the dosage every 2 to 4 weeks with the goal of discontinuation after 14 weeks has been reported to improve behavioral symptoms in some individuals with IDD.[24]

## PRINCIPLES OF CARE (cont.)

### MONITORING AND REASSESSMENT

If an antipsychotic medication is prescribed, vital signs and side effects should be monitored closely. Though side effects of these medications vary considerably, common effects can include sedation, dizziness, postural hypotension and confusion which can increase the risk of falls.[21] Extrapyramidal symptoms (e.g. tardive dyskinesia, Parkinsonism) are common in people with dementia and IDD using antipsychotics and should be monitored with standardized tools such as the Abnormal Involuntary Movement Scale (AIMS) or the Dyskinesia Identification System: Condensed User Scale (DISCUS).[25] Antipsychotic medications may lower the seizure threshold and induce seizure activity in this population, particularly for people with existing seizure disorders.[26]

Persons with dementia or IDD should be periodically reassessed to determine if antipsychotics are needed as part of regular review of the person-centered care plan. In particular, if an antipsychotic medication is prescribed in the course of treatment for behaviors resulting from medical causes such as delirium—a practice that is common but should be limited given lack of clear efficacy—the antipsychotic should be reconsidered following resolution of the delirium and should not be continued long-term.[27] It is generally not appropriate to replace an antipsychotic with an alternate class of medication such as a benzodiazepine or mood stabilizer for the purpose of sedation.

### PREVENTING CAREGIVER BURNOUT

Symptoms of stress and burnout are common among both paid and unpaid caregivers of people with dementia[28] as well as caregivers of people with IDD.[29] In addition to addressing behavioral manifestations early, it is important to link caregivers to services and supports, which could include respite care, information and assistance, counseling, and training.[30]

## SUMMARY

- Behavioral manifestations of dementia and IDD are common and require careful assessment and management.
- Physical and psychiatric causes of behavioral symptoms should be identified and treated accordingly.
- Goals of care should be discussed when dementia or IDD results in behaviors that endanger the individual or their caregivers, and a clear person-centered care plan should be made with specific behavior modification strategies.
- Non-pharmacologic approaches to care should always be attempted first unless clinically contraindicated, including helping individuals maintain a routine schedule, avoiding demanding or challenging tasks, engaging in activities that are important to the person, and focusing on creating a positive environment.
- If antipsychotics are required for behaviors that are dangerous to the individual or to others:
    - Risks and benefits should be discussed with the person or the legal representative to obtain informed consent.
    - Second generation antipsychotics are preferred, though potential side effects must be considered in the context of each individual.
    - Dosage should be started as low as possible with modest increases only when clinically indicated.
    - Symptoms should be monitored regularly.
    - Side effects should be monitored closely.
    - Medications should be discontinued through tapering when necessary if no clinical benefit is observed.
    - Taper should be attempted for all patients within 4 months of treatment with close monitoring.

## ADDITIONAL RESOURCES

National Partnership to Improve Dementia Care in Nursing Homes
https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html

CMS Hand in Hand: A Training Series for Nursing Homes
https://surveyortraining.cms.hhs.gov/pubs/ClassInformation.aspx?cid=0CMSHIH_ONL

HRSA Training Curriculum: Alzheimer's Disease and Related Dementias
https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum

The Administration on Aging's Eldercare Locator
https://eldercare.acl.gov/Public/Index.aspx

The Administration for Community Living's National Family Caregiver Support Program
https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program

National Alzheimer's and Dementia Resource Center
https://nadrc.acl.gov/

National Center on Advancing Person-Centered Practices and Systems
https://www.hsri.org/project/national-center-on-advancing-person-centered-practices-and-systems

The American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia
https://psychiatryonline.org/doi/pdf/10.1176/appi.books.9780890426807

National Nursing Home Quality Improvement Campaign's Dementia Care and Psychotropic Medications Toolkit
https://www.nhqualitycampaign.org/goalDetail.aspx?g=med

Nursing Home Toolkit: Non-Pharmacological Approaches to Address Behaviors
https://www.nursinghometoolkit.com/nonpharmacological.html

CDC's Health Aging Program: Implementing a Community-Based Program for Dementia Caregivers: An Action Guide using REACH OUT
https://www.cdc.gov/aging/caregiving/activities.htm

Alzheimer's Association 2018 Dementia Care Practice Recommendations
https://www.alz.org/media/Documents/alzheimers-dementia-care-practice-recommendations.pdf

STAR-VA Intervention for Managing Challenging Behaviors in VA Community Living Center Residents with Dementia
https://www.nhqualitycampaign.org/files/STAR-VA_Manual_2017.pdf

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