



May 22, 2025

The Honorable Robert Aderholt
Chair
Subcommittee on Labor, Health and
Human Services, Education, and Related
Agencies
House Appropriations Committee
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and
Human Services, Education, and Related
Agencies
House Appropriations Committee
Washington, DC 20515

Re: ***LHHS Report Language Request to Improve the Care and Treatment of Long-Term Care Residents with Neuropsychiatric Symptoms***

Dear Chairman Aderholt and Ranking Member DeLauro:

The undersigned members of Project PAUSE (Psychoactive Appropriate Use for Safety and Effectiveness) and other partners are writing to strongly urge you to include language in the report accompanying the fiscal year (FY) 2026 House Labor, Health and Human Services, Education, and Related Agencies (L-HHS) appropriations bill regarding steps that the Centers for Medicare and Medicaid Services (CMS) should take to eliminate an unnecessary barrier to nursing home residents receiving access to appropriate neuropsychiatric medication. Project PAUSE is an ad hoc coalition of national organizations advocating about improvements in clinical, regulatory, and legislative policies in long-term care.

Overview

People living with neurocognitive impairment experience more than memory loss. Nearly all will also experience one or more neuropsychiatric symptoms (NPS), such as psychosis, wandering, sleep issues, agitation, depression, apathy, and aggression. Effectively managing or preventing behaviors that disturb and cause harm to self and others is of the utmost importance to residents, family caregivers and providers.

Over a decade ago, CMS created a long-stay antipsychotic measure to curb the inappropriate use of antipsychotics in nursing homes. The measure is a formula of the “percent of residents who received an antipsychotic medication” calculated by dividing the number of residents on a medication by the total number of residents in the skilled nursing facility (SNF). There are only three diagnoses exempted from the measure – schizophrenia, Huntington’s disease, and Tourette’s syndrome. The measure makes no distinction between prescribing that is clinically necessary and medication use that may be inappropriate.

If CMS's goal of high-quality, patient-centered care for all beneficiaries is to be realized, long-term care residents who would benefit from antipsychotics should receive them, while those for whom they are inappropriate should not and as such, policies and programs should be aligned with this dual goal. The continued reliance on the measure could result in worse patient outcomes, increase suffering by patients with neurocognitive impairment, and cause preventable patient harm.

While individuals should not be improperly medicated, there is a legitimate, clinically appropriate use of antipsychotic medications, including recently FDA-approved medications specifically for conditions associated with neurodegenerative diseases; use of these medications is being suppressed due to this measure. The construct of the current measure pressures SNFs to reduce or eliminate antipsychotic use entirely, even when medically necessary. This has resulted in some facilities substituting less effective or riskier treatments to avoid penalties, which in turn means patients are not getting the individualized care they need and deserve. Further, patients who are stable on such medications at-home often are taken off of them once they become residents in a nursing home; quality, individualized care should not be dependent on where a patient resides. Patients who are well-managed on a specific therapy should not be taken off of it during the already stressful period of transition that accompanies leaving the home to enter a SNF.

The report language request below encourages CMS to eliminate the long-stay antipsychotic medication quality measure from the SNF Five-Star Quality Rating System. As noted earlier, this measure fails to distinguish between clinically appropriate and inappropriate use of these medications, a deficiency that has been identified by the HHS Office of the Inspector General. Additionally, the current quality measure does not ensure beneficiary safety as intended, rather it has led to unintended consequences that negatively impact patient care, health, and well-being.

Furthermore, Congress and CMS should develop and implement effective policies to curb the inappropriate use of antipsychotics and ensure access and appropriate use of these medications by patients who need them. The first step toward achieving this dual goal is retirement of the measure and modifying the Medicare Data Set (MDS) to ensure sufficient documentation by the patient's physician and independent facility pharmacist, as outlined in the draft report language below for the committee's consideration.

**Recommended Report Language Request for FY2026 Labor-HHS-Education
Appropriations Bill**

Long-term Care Facility Metrics.—The Committee supports efforts to improve the quality of care and outcomes for individuals served by long-term care facilities,

including skilled nursing facilities, and recognizes that many residents of these facilities have a range of chronic and disabling conditions, including neuropsychiatric symptoms associated with Alzheimer's disease and related dementias, neurodegenerative disorders, and serious mental health issues. The Committee notes concerns that residents of these facilities not be treated with so-called chemical restraints. However, the Committee also is concerned that too many residents with neuropsychiatric symptoms who could benefit from FDA-approved treatments do not receive appropriate care and treatment due to a range of factors, including measures that impact the five-star rating system, stigma, and lack of understanding and awareness of appropriate treatment. In 2021, the HHS OIG found that the current CMS measures related to the use of antipsychotics are insufficient and do not distinguish appropriate from inappropriate use. CMS is directed to retire the current measure which is not able to sufficiently capture information regarding appropriate or inappropriate use of antipsychotics and negatively impacts a physician's ability to appropriately treat patients, arbitrarily based on the setting of care. CMS is directed to continue collecting data on the use of the medications and amend the Medicare Data Set to ensure sufficient documentation by the patient's physician and independent facility pharmacist to demonstrate appropriate use of antipsychotics in skilled nursing facilities. The Committee requests that CMS provide an update on progress retiring this measure in the fiscal year 2027 CJ.

Clinically necessary care must be within reach for older adults living with Alzheimer's and related diseases. We remain greatly concerned that this outdated CMS "quality" measure is gravely thwarting timely access to life-enhancing and, ultimately, lifesaving medications and therapies for beneficiaries with neurocognitive impairment. Further, we believe the aforementioned actions will help modernize CMS quality standards and help ensure beneficiaries have access to the clinical care their providers recommend and their loved ones want them to receive.

Thank you for your consideration of this request and for your leadership in advancing high-quality care for patients with Alzheimer's and related neurocognitive impairment.

Sincerely,

Alliance for Aging Research
American Society of Consultant Pharmacists
American Association of Post-Acute Care Nursing (AAPACN)
American Association for Geriatric Psychiatry
American Association of Psychiatric Pharmacists
Caregiver Action Network
Depression and Bipolar Support Alliance (DBSA)
HealthyWomen

Huntington's Disease Society of America
LeadingAge
National Community Pharmacists Association
Partnership to Fight Chronic Disease
Rural Minds
The Balm In Gilead, Inc.
Voices of Alzheimer's