



**Center for Clinical Standards and Quality/Survey & Certification Group**

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**DATE:** April 11, 2014

**TO:** State Survey Agency Directors

**FROM:** Director  
Survey and Certification Group

**SUBJECT:** Interim report on the CMS National Partnership to Improve Dementia Care in Nursing Homes: Q4 2011 – Q1 2014

**Memorandum Summary**

**Report** – The Centers for Medicare & Medicaid Services (CMS) has released an interim report that discusses the history of the National Partnership to Improve Dementia Care, summarizes activities to date, provides reasons for early progress and outlines next steps for future Partnership efforts.

**Background**

In 2011, The Office of the Inspector General (OIG) of the Department of Health and Human Services released a report underscoring the high use of atypical antipsychotic medications for “off-label” indications among nursing home residents. According to this report, 83% of atypical antipsychotic drug claims were for elderly nursing home residents who had not been diagnosed with a condition for which antipsychotic medications were approved by the FDA.<sup>1</sup>

Nursing home advocates and others expressed concern for the high rates of antipsychotic medication use and urged CMS to do more to address this persistent threat to quality and safety. In early 2012, in response to the OIG report, as well as concerns from advocates and commitment from provider associations and other stakeholders, CMS established the National Partnership to Improve Dementia Care in Nursing Homes.

**National Partnership**

The National Partnership seeks to optimize quality of life for residents in America’s nursing homes by improving comprehensive approaches to the psychosocial and behavioral health needs

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<sup>1</sup> Levinson DR. Medicare Atypical Antipsychotic Drug Claims for Elderly Nursing Home Residents. Department of Health and Human Services Office of Inspector General Report (OEI-07-08-00150)05-04-2011 accessed at <https://oig.hhs.gov/oei/reports/oei-07-08-00150.pdf>

of all residents, especially those with dementia. This robust public-private collaboration has engaged providers and provider associations, clinicians, researchers, advocates, government agencies, residents and families in every state and outlines a multidimensional strategy to address this public health issue. Although the initial focus of the Partnership has been on reducing the use of antipsychotic medications, the overall goal of this Partnership is to enhance the use of non-pharmacologic approaches and person-centered dementia care practices.

This report outlines the history of the National Partnership, summarizes activities to date, provides insight into the early progress of the initiative and outlines next steps for the future.

**Attachments** – 3

Attachment A – Interim Report Overview

Attachment B – Interim Report – CMS National Partnership to Improve Dementia Care in Nursing Homes: Q4 2011 – Q1 2014

Attachment C – Appendices – Appendix A – Lists – State Coalition Leads & Master Participant

Appendix B – List – Selected Accomplishments to Date

Appendix C – Letters – Samples Sent to Nursing Homes

Appendix D – Examples – Programs & Resources

For questions on this memorandum, please contact Michele Laughman via email at [dnh\\_behavioralhealth@cms.hhs.gov](mailto:dnh_behavioralhealth@cms.hhs.gov).

**Effective Date:** Immediately.

/s/

Thomas E. Hamilton

cc: Survey and Certification Regional Office Management

# Interim Report Overview

## Background

As many as one in four nursing home residents receive at least one antipsychotic medication, and many of those residents have dementia. The Office of the Inspector General (OIG) of the Department of Health and Human Services released a report in 2011, underscoring the high use of atypical antipsychotic medications for off-label indications among nursing home residents. These medications have a number of serious side effects; an increased risk of death in this population led to a Federal Drug Administration (FDA) black box warning related to antipsychotic use in older adults with dementia.

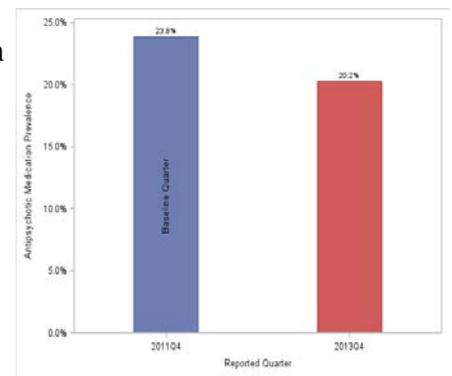
In the fall of 2011 a group of nursing home advocates from several organizations met with CMS Administrator Donald Berwick and senior CMS leaders; advocates expressed concern for the high rate of antipsychotic medication use in nursing homes. The meeting motivated CMS to establish the National Partnership to Improve Dementia Care, catalyzed a broad range of activities by provider organizations and others, and ultimately led to the formation of state-based coalitions to improve dementia care in every State.

This interim report:

- Provides a detailed history of the National Partnership
- Presents current data trends for antipsychotic use and enforcement activity by State and CMS Region
- Describes and catalogues specific contributions of various partnering organizations
- Summarizes Partnership activities to date
- Explores reasons to explain the early progress of the initiative
- Outlines future goals and next steps.

## Current Data Trends

- Over 18 months, the national prevalence of antipsychotic use in long-stay NH residents was reduced by 15.1% (the prevalence rate decreased from 23.8% to 20.2%) and every CMS region showed at least some improvement. Some States showed much more improvement than others, for example Georgia reduced their rate by 26.4% and North Carolina saw a 27.1% reduction. Short-stay incidence rates improved as well.
- More remains to be done to focus nursing home care on person-centered care principles, individualized approaches and a systems-based framework for quality improvement. Many nursing homes across the country demonstrated that these changes may be achievable without a substantial investment in additional resources (and in some cases, even saved resources). This report documents how CMS and its partners are finding new ways to implement practices that enhance quality of life for people with dementia, protecting them from substandard care and promoting goal-directed, person-centered care for every resident.





Report on the CMS National Partnership to  
Improve Dementia Care in Nursing Homes: Q4  
2011 – Q1 2014

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April 1, 2014

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## Executive Summary

### Why This Initiative? Why Now?

As many as one in four nursing home residents receive at least one antipsychotic medication, and many of those residents have dementia. These medications have a number of serious side effects; an increased risk of death in this population led to a Federal Drug Administration (FDA) black box warning related to antipsychotic use in older adults with dementia. Analyses by the Centers for Medicare and Medicaid Services (CMS) and a number of researchers revealed that in many cases, these medications are used inappropriately, for too long and at too high a dose.

Alternative, non-pharmacological approaches to optimize care for people with dementia living in nursing homes have not been widely implemented to date.

In the fall of 2011, a group of nursing home advocates from several organizations met with CMS Administrator Donald Berwick and senior CMS leaders. The advocates expressed concern for the high rates of antipsychotic medication use in nursing homes and asked if CMS could do more to address this persistent threat to quality and safety. It was the strong voice of the advocates and their unwavering belief that better care could be achieved that motivated CMS to establish the National Partnership, catalyzed a broad range of activities by provider organizations and others, and ultimately led to the formation of coalitions to improve dementia care in every State.

This report provides a history of the National Partnership, summarizes activities to date, provides some reasons to explain the early progress and outlines next steps.

### Background

The Omnibus Budget and Reconciliation Act of 1987 (often referred to as OBRA87 or the nursing home reform law) established a detailed regulatory structure designed to transform the way people live their lives in America's nursing homes; specifically, this landmark legislation requires every nursing home to "provide care and services in order for each resident to attain or maintain his/her highest practicable level of physical, mental and psychosocial well-being."

Residents who exhibit behaviors related to their dementia present a unique set of challenges to nursing homes. Dementia care specialists and practitioners advocate for a transformation of nursing home culture away from the medical, institutional model to a more person-centered, supportive community with the knowledge, skills and expertise to meet the needs of persons with dementia as envisioned by the nursing home reform law.

In 2011, The Office of the Inspector General (OIG) of the Department of Health and Human Services released a report underscoring the high use of atypical antipsychotic medications for "off-label" indications among nursing home residents. According to this report, 83% of atypical antipsychotic drug claims were for elderly nursing home residents who had not been diagnosed with a condition for which antipsychotic medications were approved by the FDA. In early 2012,

in response to this report, as well as concerns from advocates and others about the persistently high rate of antipsychotic medication use in nursing home residents with dementia, CMS established the National Partnership to Improve Dementia Care in Nursing Homes, a unique public-private partnership that outlined a multidimensional strategy to address this public health issue.

### Summary of Activities

- The CMS team, with input from its partners, developed an overall strategic plan for the Partnership with an initial goal of reducing the national prevalence of antipsychotic medication use in long-stay nursing home residents by at least 15% by December 31<sup>st</sup>, 2012. CMS hosted a technical expert panel of international dementia practitioners, clinicians, researchers, advocates and family members that established goals and strategies for the National Partnership (April, 2012).
- CMS worked with consumer advocates, Quality Improvement Organizations (QIOs) and Advancing Excellence Local Area Networks for Excellence (LANES) to identify existing groups or establish new State Coalitions for dementia care with leaders/champions in every State. (For a list of State Coalition leads and Master List of all partners, see Appendix A).
- CMS began conducting regular (monthly, quarterly) conference calls with States, regions and national calls with State Coalitions that established communities of practice. (See Appendix B – Selected Accomplishments, for a list of State and National calls, calls with professional associations, conference presentations and individual outreach to facilities & dates). In addition to calls with State Coalitions, in 2013, CMS and its partners increased direct outreach to nursing facilities, hospitals, advocates, professionals and professional associations. CMS Central Office Survey and Certification Group also conducted calls with five of the top ten multi-state, multi-facility chain nursing homes, to learn how those organizations are reducing unnecessary antipsychotic use in their facilities, and specifically how they are targeting low performing facilities within those corporations.
- Several partner organizations such as State survey agencies, regional offices and professional organizations sent emails or letters to members or to nursing homes with high rates of antipsychotic use. (For sample letters, see Appendix C).
- Over the past two years, CMS (particularly the Quality Improvement Group) and its partners developed numerous resources and made them available in the public domain. In particular, resources targeting prescribers as well as consumer materials for residents/families were produced and widely disseminated. (For selected examples of national, State and local programs offered as part of the initiative, see Appendix D).

- CMS and Advancing Excellence deployed a new webpage dedicated to the National Partnership (<https://www.nhqualitycampaign.org>). This website includes an extensive set of webpages specific to the National Partnership with detailed technical assistance, tools and educational resources all available for free and in the public domain.
- Hand-in-Hand, a series of six DVDs, was created and produced by CMS, along with a team of national dementia care practitioners and expert reviewers (including advocates and family members). This training program was distributed for free to every nursing home in the country. <http://www.cms-handinhandtoolkit.info/Index.aspx> .
- CMS began public reporting of incidence (short-stay residents) and prevalence (long-stay residents) of antipsychotic medication use for each nursing home on Nursing Home Compare beginning in July, 2012. In addition, CMS sends quarterly updates with State and national averages and rates for each facility in the State to the State Coalition leads, as well as many professional associations who then share the reports with their State chapter leadership. This enabled CMS and its partners to track improvement, as well as to identify facilities with persistently high rates and little or no change. Beginning in 2013, CMS and State Coalitions increased direct outreach to those homes in several States.
- In order to facilitate increased scrutiny during the survey process, CMS implemented enhanced guidance for State surveyors in Appendix PP of the State Operations Manual. The purpose of these revisions was to improve surveyors' ability to detect deficient practices related to dementia care and unnecessary antipsychotic medication use, and to ensure that residents with dementia who are on an antipsychotic medication are included on all standard surveys. This included more detailed guidance on §483.25 Quality of Care, Care and Services of a Resident with Dementia, F tag 309; and revisions/clarifications to §483.25(l) Unnecessary Medications, F 329. <http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-13-35.pdf>
- CMS produced a series of three mandatory training programs for all State surveyors (2012-2013). These training videos are also available to the public and may be accessed at <http://surveyortraining.cms.hhs.gov/pubs/AntiPsychoticMedHome.aspx>.

To date, 75% of surveyors nationally completed the training and the remainder are scheduled. In 2014, CMS began quarterly calls with regional office and survey agency leaders to address enforcement issues and discuss surveyor feedback on the new guidance.

- A number of research initiatives related to dementia care and antipsychotic use were already underway in 2011, and more were funded or expanded as part of the National

Partnership. An international group of researchers convened regular conference calls over the past two years, to share new findings and learn about one another's studies. In addition:

- CMS contracted with Health Management Solutions (HMS) and researchers at the University of Massachusetts Medical School Meyers Primary Care Institute to conduct a descriptive study in order to better understand the reasons for use of antipsychotic medications in nursing home residents with dementia.
- The Commonwealth Fund sponsored a study by the Center for Medicare Advocacy and Dean Lerner Consulting in which reviewers examined annual and complaint survey inspection reports from seven States. Specifically, they reviewed the scope and severity of 295 citations at F329 in which antipsychotic medications were identified as unnecessary drugs.  
<http://www.medicareadvocacy.org/cma-report-examining-inappropriate-use-of-antipsychotic-drugs-in-nursing-facilities/>
- A project to develop and test an integrated, clinical database using data from the minimum data set (MDS) and the prescription monitoring program (PMP) in Illinois is currently underway.

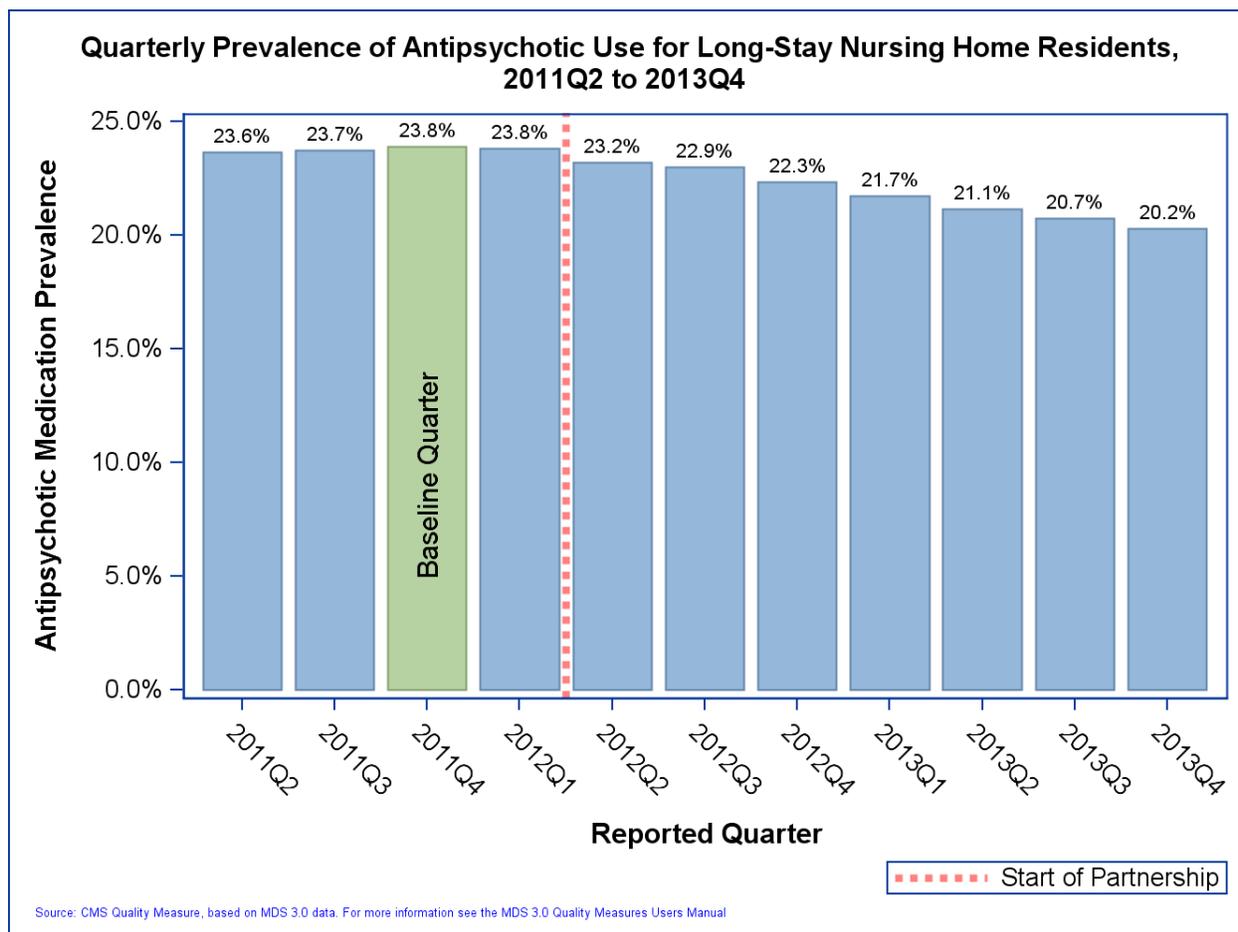
## Current Data Trends

There are two new measures of antipsychotic medications that were posted on the Nursing Home Compare (NHC) website beginning July 2012. The new measures include an incidence measure that assesses the percentage of short-stay residents that are given an antipsychotic medication after admission to the nursing home, and a prevalence measure (used to track the progress of the National Partnership) that assesses the percentage of long-stay residents that are receiving an antipsychotic medication.

- Over 18 months, the national prevalence of antipsychotic use in long-stay NH residents was reduced by 15.1% (the rate decreased from 23.8% to 20.2%) and every CMS region showed at least some improvement. Some States showed much more improvement than others, for example Georgia reduced their rate by 26.4% and North Carolina saw a 27.1% reduction (see Figures 1-3, pgs. 21-23). Short-stay incidence rates improved as well (see Figures 4-6, pgs. 24-26).
- With respect to enforcement, CMS examined citation patterns at F329 by State and Region, and will continue to track these citations including scope and severity (see Tables 1-4 and Figure 7, pgs. 27-29). It should be noted that not all citations at F329 relate to antipsychotic medications specifically.
- CMS reviewed mental/neurological diagnoses (Table 5, p. 30) and rates of use for other psychopharmacologicals, such as anxiolytics and sedative/hypnotics (Table 6, p. 30).

Data as of 3/2014 suggest a slight increase in the percent of nursing home residents who received a diagnosis of schizophrenia, and a small decline in the use of sedative-hypnotics, as well as a significant reduction in antipsychotics during the initiative.

**Figure1 (from pg. 21): Quarterly Prevalence of Antipsychotic Use for Long-Stay Nursing Home Residents, 2011Q2 to 2013Q4**



## Reasons for Early Progress of the National Partnership

The CMS National Partnership convened broad-based, grass roots stakeholder groups in every State, dedicated to the goal of reducing unnecessary antipsychotic use and improving dementia care in every nursing home. By making the campaign about comprehensive, person-centered dementia care for each resident, the fundamental goal of eliminating all threats to resident dignity and quality of life resonated across providers, regulators, advocates, and others.

The coalitions at the State level were effective in translating stories from the field, with a strong focus on leading with core values, obtaining input from frontline workers, residents and families with respect to systems change. As an example of an important systems change, one of the most significant changes that CMS has seen through the National Partnership is that some facilities are adopting a systematic approach to gradual dose reduction or GDRs. In many cases, facilities

changed their practices to include a regular and systematic review by the interdisciplinary team of all residents with dementia who are receiving an antipsychotic and systemic action including a specific plan to evaluate whether a GDR is indicated for each of those residents. Opportunities exist to ensure that these practices are disseminated to all facilities nationwide.

CMS maintained a focus on regulatory consistency and enforcement since the beginning of the National Partnership. While many States saw improvement in their rates of antipsychotic use, certain regions of the country continue to experience higher rates than others. CMS conducts more frequent calls with regional office and State agency staff in those States in order to review performance and ensure consistent regulatory standards.

In terms of reducing unnecessary antipsychotic medication use, surveyors were directed to speak with physicians, nurse practitioners, and other prescribers about how decisions are made to use or not to use antipsychotic medications in residents with dementia. Surveyors were also directed to identify whether or not there is effective communication among the nursing staff, medical team, consultant pharmacist and family around prescribing decisions. Revised guidance at F309 and F329 instructs surveyors to consider communication among disciplines, across shifts and between weekday and weekend staff, as well as between staff and prescribers, behavioral health teams and family members.

Regional offices are working with State agencies on Federal surveys, to ensure that State surveyors are knowledgeable and able to identify current dementia care practices. A number of State-based pay-for-performance or value-based purchasing programs (managed Medicaid and others) that incentivize facilities for providing evidence of enhanced person-centered care practices or for tracking data on antipsychotic medication reduction are in place.

Next steps for sustaining the National Partnership include:

1. CMS will set new goals for the partnership in 2014
2. CMS will revise guidance as needed, based on surveyor feedback and enforcement trends
3. CMS will continue to monitor outcomes related to the initiative, including direct outreach, deficiency citation patterns and other efforts
4. CMS will continue to facilitate patient outcome and health systems research on this issue.

The National Partnership to Improve Dementia Care is a public-private partnership that encourages grassroots outreach, collaboration and commitment by individuals and organizations in local communities, States and regions. Furthermore, it engages State and Federal policy-makers, Medicaid, Medicare and other government agencies in working together on critical policy issues. These combined efforts focus on ensuring high quality dementia care in nursing homes, as well as supporting direct care workers and facilities that are striving to improve, and holding facilities accountable if they are not in compliance with State and Federal regulations. Clearly, much more remains to be done to focus nursing home care on person-centered care principles, individualized approaches and a systems-based framework for quality improvement. Many nursing homes across the country demonstrated that these changes may be achievable without a substantial investment in additional resources (and in some cases, even saved resources). CMS and its partners are committed to finding new ways to implement practices that enhance quality of life for people with dementia, protect them from substandard care and promote goal-directed, person-centered care for every resident.

# Background

## Nursing Home Reform and Dementia Care

The Omnibus Budget and Reconciliation Act of 1987 (often referred to as OBRA87 or the nursing home reform law) established a detailed regulatory structure designed to transform the way people live their lives in America's nursing homes; specifically, this landmark legislation requires every nursing home to "provide care and services in order for each resident to attain or maintain his/her highest practicable level of physical, mental and psychosocial well-being."<sup>1</sup> Among other things, OBRA 87 described processes and systems required for comprehensive resident assessments, qualifications of nursing home staff, expectations for medical care and the right to individualized, person-centered, goal-directed care planning.

The right to be free from physical and chemical restraints and to be treated with dignity and respect are central tenets of the nursing home reform law. Over the past several years, improving national trends were reported in a number of nursing home quality measures, such as lower rates of facility acquired pressure ulcers in low risk residents and significantly lower rates of physical restraint use<sup>2</sup>. However, despite implementation of provisions in OBRA87, concerns about quality of care and quality of life in nursing homes persist.<sup>3,4</sup> OBRA87 outlines the requirements to ensure goal-directed care planning, person-centered care and quality of life for all nursing home residents; however, residents with cognitive impairment such as dementia are at particularly high risk for failure to achieve these goals.

Residents who exhibit behaviors related to their dementia present a unique set of challenges to nursing homes. These individuals may be at higher risk for resident-to-resident altercations, adverse events and elder abuse if staff is not properly trained in dementia care<sup>5</sup>, and if resources to provide that care are not supported by leadership. Historically, the health care system, including the culture in nursing homes, required residents to adapt to an institutional, routinized health care environment instead of meeting residents "in their world."<sup>6</sup> Dementia care specialists and practitioners advocate for a transformation of nursing home culture to a more person-

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<sup>1</sup> Omnibus Budget Reconciliation Act of 1987. P.L. 100-203. Subtitle C. *The Nursing Home Reform Act*. 42 U.S.C. 1395i-3(a)-(h)(Medicare); 1396r (a)-(h)(Medicaid).

<sup>2</sup> Abt Associates, Inc. and Colorado Foundation for Medical Care. (June 7<sup>th</sup>, 2013). Nursing Home Compare Five-Star Quality Rating System: Year Three Report. Prepared for The Centers for Medicare and Medicaid Services (CMS).

<sup>3</sup> Schnelle, JF, Karuza, J., Katz PR. (2013). Staffing, quality, and productivity in the nursing home. *J Am Med Dir Assoc*, 14(11), 784-786. doi:10.1016/j.jamda.2013.08.017.

<sup>4</sup> Hyer, K., Thomas, KS, Branch LG, Harman, JS, Johnson, CE, Weech-Maldonado, R. (2011). The influence of nurse staffing levels on quality of care in nursing homes. *The Gerontologist*, 51(5), 610-616. doi:10.1093/geront/gnr050.

<sup>5</sup> Pillemer, K., Chen, EK, van Haitsma, KS, Teresi, J., Ramirez, M., Silver, S., Sukha, G., Lachs, MS. (2012). Resident-to-Resident Aggression in Nursing Homes: Results from a Qualitative Event Reconstructive Study. *The Gerontologist*, 52(1): 24-33.

<sup>6</sup> Power, G. Allen. (2010). *Dementia Beyond Drugs: Changing the Culture of Care*. Baltimore, Maryland: Health Professions Press.

centered, supportive community with the knowledge, skills and expertise to meet the needs of persons with dementia as envisioned by the nursing home reform law.<sup>7,8</sup>

### Antipsychotic Medication Use in Nursing Homes

The prevalence of antipsychotic medication use in nursing homes is high. Approximately one-quarter to one-third of nursing home residents were prescribed antipsychotic therapy in 2011.<sup>9</sup> In one study, 22% of residents with dementia who were prescribed an antipsychotic for an off-label use did not have behavioral symptoms and 29.5% had non-aggressive behavioral symptoms.<sup>10</sup> In some cases, patients may have a clinical indication or psychiatric diagnosis. In other situations these medications were used off-label to treat mild behavioral symptoms such as wandering, or as a sedative or chemical restraint for non-approved uses such as “crying” or “resisting care.”<sup>11</sup>

Antipsychotic drug therapy is not approved for treatment of behavioral and psychological symptoms of dementia. Based on evidence of serious side effects, including an increased risk of death, in 2005 and 2008 the FDA issued a Black Box warning for antipsychotic use in people with dementia.<sup>12</sup> Despite these warnings, and a lack of efficacy noted in several studies,<sup>13,14,15</sup> these agents continue to be used commonly to treat behavioral or psychological symptoms of dementia (BPSD).<sup>16</sup>

In 2011, The Office of the Inspector General (OIG) of the Department of Health and Human Services released a report underscoring the high use of atypical antipsychotic medications for “off-label” indications among NH residents. According to this report, 83% of atypical

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<sup>7</sup> Zimmerman, S. Shier, V., Saliba, D. (2014). Transforming Nursing Home Culture: Evidence for Practice and Policy. *The Gerontologist*. 54(S1). S1-S5.

<sup>8</sup> <http://www.medicareadvocacy.org/cma-report-examining-inappropriate-use-of-antipsychotic-drugs-in-nursing-facilities/>

<sup>9</sup> CMS Quality Measure, based on MDS 3.0 data.

<sup>10</sup> Crystal S, Olfson M, Huang C, et al. Broadened use of atypical antipsychotics: safety, effectiveness, and policy challenges. *Health Aff*. 2009;28:w770–781.

<sup>11</sup> Tjia, J., Gurwitz, JH, Briesacher, BA. (2012). Challenge of Changing Nursing Home Prescribing Culture. *The American Journal of Geriatric Pharmacotherapy*. 10(1): 37-46.

<sup>12</sup> US Food and Drug Administration. Public Health Advisory April 2005: Death with antipsychotics in elderly patients with behavioral disturbances. <http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/DrugSafetyInformationforHealthcareProfessionals/PublicHealthAdvisories/UCM053171>. Accessed March 1, 2014.

<sup>13</sup> Ballard, C., Waite, J. (2006). The effectiveness of atypical antipsychotics for the treatment of aggression and psychosis in Alzheimer’s disease. *Cochrane Database Systematic Review*. 25(1); CD003476.

<sup>14</sup> Crystal S, Olfson M, Huang C, et al. Broadened use of atypical antipsychotics: safety, effectiveness, and policy challenges. *Health Aff*. 2009;28:w770–781.

<sup>15</sup> Maher, A. R., Maglione, M., Bagley, S., Suttrop, M., Hu, J. H., Ewing, B., . . . Shekelle, P. G. (2011). Efficacy and comparative effectiveness of atypical antipsychotic medications for off-label uses in adults: a systematic review and meta-analysis. *JAMA*, 306(12), 1359-1369. doi: 10.1001/jama.2011.1360.

<sup>16</sup> Tjia, J., Gurwitz, JH, Briesacher, BA. (2012). Challenge of Changing Nursing Home Prescribing Culture. *The American Journal of Geriatric Pharmacotherapy*. 10(1): 37-46.

antipsychotic drug claims were for elderly NH residents who had not been diagnosed with a condition for which antipsychotic medications were approved by the FDA.<sup>17</sup>

There are a number of possible reasons for the high use of antipsychotic medications to address behaviors in people with dementia living in nursing homes. A relative lack of staff training and/or relevant therapeutic recreation (meaningful activities) for people with dementia may be contributing factors in some facilities.<sup>18</sup> A culture of prescribing may have evolved in part due to the perception that these medications are effective in treating behavioral symptoms of dementia and that non-pharmacological interventions may be less effective or too time-consuming to be part of standard nursing home care for most residents.<sup>19</sup> Lower registered nurse (RN) staffing levels have also been associated with higher antipsychotic use.<sup>20</sup>

One question was, “Why are so many residents continued on these medications for long periods of time?” despite studies showing that behavioral and psychological symptoms of dementia do not worsen when many patients are tapered off antipsychotics.<sup>21</sup> Even with this evidence and the risk of serious side effects, patients with dementia often remain on antipsychotic medications for extended periods of time and at higher than recommended dosages. Physicians with more knowledge of non-pharmacologic interventions may be more likely to consider those therapies;<sup>22</sup> however, some studies suggest that providers may not choose a non-pharmacologic approach because of nursing staff requests for drug therapy.<sup>23</sup>

A culture of prescribing is associated with the higher likelihood of a resident being placed on an antipsychotic after nursing home admission.<sup>24</sup> Nursing homes with high antipsychotic prescribing rates are three times more likely than facilities with low prescribing rates to use antipsychotic medication in residents regardless of clinical indication. In some studies, higher antipsychotic use is more often found in for-profit facilities, whereas decreased antipsychotic use was associated with chain membership, higher levels of competition, and higher Medicaid

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<sup>17</sup> Levinson DR. (May, 2011). Medicare atypical antipsychotic drug claims for elderly nursing home residents. Department of Health and Human Services Office of the Inspector General. OEI-07-08-00150.

<sup>18</sup> Thomas, W., & Stermer, M. (1999). Eden Alternative Principles hold promise for the future of long-term care. *Balance*, 3(4), 14-17.

<sup>19</sup> Cohen-Mansfield, J., Thein, K., Marx, MS, Dakheel-Ali, M. (2012). What are the barriers to performing non-pharmacological interventions for behavioral symptoms in the nursing home? *JAMDA*, 3(4); 400-5.

<sup>20</sup> Castle, NG, Meyers, S. (2006). Mental Health Care Deficiency Citations in Nursing Homes and Caregiver Staffing. *Administration and Policy in Mental Health and Mental Health Services Research*, 33(2); 215-225.

<sup>21</sup> Declercq T, Petrovic M, Azermai M, Vander Stichele R, De Sutter AI, van Driel ML, Christiaens T. (March 28, 2013). Withdrawal versus continuation of chronic antipsychotic drugs for behavioural and psychological symptoms in older people with dementia. *Cochrane Database Systematic Review*. CD007726. doi: 10.1002/14651858.CD007726.pub2.

<sup>22</sup> Janzen, S., Zecevic, A., Klobeck, M., & Orange, J. B. (2013). Managing agitation using nonpharmacological interventions for seniors with dementia. *Journal of Alzheimer's Disease and Other Dementias*, 28(5), 524-32.

<sup>23</sup> Janzen, S., Zecevic, A., Klobeck, M., & Orange, J. B. (2013). Managing agitation using nonpharmacological interventions for seniors with dementia. *Journal of Alzheimer's Disease and Other Dementias*, 28(5), 524-32.

<sup>24</sup> Chen Y, Briesacher BA, Field TS, et al. Unexplained variation across US nursing homes in antipsychotic prescribing rates. *Arch Intern Med*. 2010;170:89-95.

reimbursement rates<sup>25</sup>. CMS data also reflect regional and State-to-State variability in prescribing patterns (see Figure 3, p. 23 and Figure 6, p. 26).

### Medicare Costs

The House Ways and Means Committee (June, 2011) expressed concerns to CMS about high Medicare expenditures for these drugs, and questioned whether these agents were producing positive outcomes and providing value for patients who receive them.<sup>26</sup> From January 1 through June 30, 2007 claims for elderly NH residents accounted for 20% of the total 8.5 million claims for atypical antipsychotic drugs for all Medicare beneficiaries, with claims for NH residents amounting to \$309 million.<sup>27</sup> Part D spending on antipsychotic drugs in 2011 totaled \$7.6 Billion, which was the second highest class of drugs, accounting for 8.4% of Part D spending.<sup>28</sup>

## A Call to Action: CMS National Partnership to Improve Dementia Care

In response to these concerns and in partnership with nursing home advocacy organizations, professional associations and others, in late 2011 the Centers for Medicare and Medicaid Services (CMS) began to refocus on the high prevalence of antipsychotic medication use in nursing home residents with dementia. In early 2012, CMS established the National Partnership to Improve Dementia Care in Nursing Homes, a unique public-private partnership that employed a multidimensional approach to addressing this public health issue. The following summarizes the history of the National Partnership:

### National Goal, Strategy, Launch of the Initiative

- The CMS team, with input from its partners, developed an overall strategic plan for the Partnership with an initial goal of reducing the national prevalence of antipsychotic medication use in long-stay nursing home residents by at least 15% by December 31<sup>st</sup>, 2012.
- CMS held a national kick-off event and posted a video of the event on You Tube and the CMS website (March, 2012) [http://www.youtube.com/watch?v=U1\\_rpO0bwbM](http://www.youtube.com/watch?v=U1_rpO0bwbM).
- Advancing Excellence in collaboration with the Rothschild Foundation, hosted a technical expert panel of international dementia practitioners, clinicians, researchers, advocates and family members at CMS that established goals and strategies for the

<sup>25</sup> Castle, NG, Meyers, S. (2006). Mental Health Care Deficiency Citations in Nursing Homes and Caregiver Staffing. *Administration and Policy in Mental Health and Mental Health Services Research*, 33(2); 215-225.

<sup>26</sup> <http://www.hhs.gov/asl/testify/2011/11/t20111130a.html>

<sup>27</sup> <http://www.hhs.gov/asl/testify/2011/11/t20111130a.html>

<sup>28</sup> <http://www.medpac.gov/documents/Jun13DataBookEntireReport.pdf>

National Partnership (April, 2012). Summary documents from that meeting focused on an individualized, person-centered approach to clinical assessment, so that residents who were on an antipsychotic medication without a valid clinical indication would be reviewed and considered for a gradual dose reduction, and new residents admitted on an antipsychotic medication would be rapidly reviewed. This individualized approach also emphasized that some residents with serious mental illness who have a valid reason for the use of these medications should be maintained on these medications if indicated and supported by documentation in the medical record.

### **State Coalitions, Partnerships and Communities of Practice**

- CMS worked with the Quality Improvement Organizations (QIOs) and Advancing Excellence Local Area Networks for Excellence (LANES) to identify existing groups or establish new State coalitions for dementia care with leaders/champions in every State. Members include professional associations, advocacy groups, government agencies, ombudsman, residents, families, researchers, clinicians and others. State coalitions are open to anyone and the purpose is to serve as a clearinghouse for activities, tools and resources around dementia care in nursing homes for that State. These groups share best practices, host educational programs, engage in peer-to-peer mentoring, conduct outreach to facilities and groups that have not yet become engaged in the initiative. CMS maintains regular telephone contact with each State Coalition. In many cases, these coalitions later merged with the QIO or LANE for that State, in an effort to synchronize and streamline quality improvement work in nursing homes. Communication among State Coalitions and between States and CMS was facilitated by establishing a national mailbox dedicated to the initiative: [DNH\\_BehavioralHealth@cms.hhs.gov](mailto:DNH_BehavioralHealth@cms.hhs.gov). (For a list of State Coalition leads and Master List of all partners in the initiative, see Appendix A).
- CMS conducts regular (monthly, quarterly) conference calls with States, regions and advocates, and national calls with State Coalitions that established communities of practice. These calls enabled initiative partners to share best practices and brainstorm together about the challenges to improving dementia care in their facilities, States and Regions. Guest speakers from around the US and other countries presented results of program implementation, research and government strategies to reduce the unnecessary use of antipsychotic medications and enhance the use of non-pharmacological approaches including activities, exercise and other programs as well as increased staff training on how to identify the underlying causes of behaviors that may occur in people with dementia. (See Appendix B – Selected Accomplishments, for a list of State and National calls, calls with professional associations, direct outreach to facilities, conference presentations & dates).
- In addition to calls with State Coalitions, in 2013, CMS and its partners increased direct outreach to nursing facilities, hospitals, professionals and professional associations such

as the American Health Care Association (AHCA), Leading Age, American Medical Directors Association (AMDA), American Society of Consultant Pharmacists (ASCP), American Association for Geriatric Psychiatry (AAGP), American Psychological Association (APA), Gerontological Advanced Practice Nurses Association (GAPNA) and others to motivate their members to take action.

Direct outreach to nursing homes that continue to demonstrate a high prevalence of antipsychotic medication use without improvement enabled State coalition and national leaders to provide specific guidance to targeted facilities in several States that may not have been aware of available tools and resources. Peer-to-peer mentoring during these outreach efforts involved directors of nursing, administrators, physicians and advanced practice nurses connecting with colleagues to provide information and support for how to implement and sustain structured programs to reduce unnecessary antipsychotic use.

- Several partner organizations such as State survey agencies, CMS regional offices and professional organizations (e.g., AHCA, AMDA, ASCP) sent emails or letters to members or to nursing homes with high rates of antipsychotic use. This communication provided facility level data with State and National benchmarks to increase awareness about an individual facility's data, and to enable individual organizations to consider specific action steps. The communication also served to connect individual facilities with peers, tools and resources to promote positive dementia care practices. (For sample letters, see Appendix C).
- In 2013, CMS included work on dementia care and unnecessary antipsychotic medication reduction in the Quality Improvement Organization (QIO) 10<sup>th</sup> scope of work – this also became a focus of the Nursing Home Quality Care Collaboratives (NHQCCs) through the Learning and Action Networks. The Advancing Excellence Campaign also made work on dementia care and medication management priorities for State Local Area Networks for Excellence (LANES). The Medicare Part D Workgroup held several calls and meetings with member organizations focusing on the National Partnership; other Federal agencies that actively participated in the initiative include SAMHSA, CDC, HRSA and the Veteran's Administration.

Below is a quote from State Lead Cindy DePorter, MSSW, Quality Evaluative Systems Manager for Nursing Home Licensure and Certification, describing the history of the North Carolina Coalition, a State that achieved a 27.1% reduction in the rate of antipsychotic use:

“In April of 2012 at a conference in Baltimore, CMS rolled out the plan for the National Partnership to Improve Dementia Care along with the goal of 15% reduction in antipsychotic medication use by the end of that year. I went back to North Carolina and we had a discussion with our partners. We planned a strategy to provide training to nursing homes and surveyors on CMS' initiative.

We started with pharmacy training on antipsychotics, and also got a physician's and LTC Ombudsman's perspectives. The QIO followed by explaining the expectations from the survey point of view: what would the surveyors be looking for? By the end of 2012, F 329 came into the top ten deficiencies in North Carolina. The North Carolina State Agency also contacted the top twenty nursing homes in the State that had the highest antipsychotic use and discussed their plans to evaluate and address this issue.

In following up with strategies to address resident behavior, North Carolina utilized CMP money to support the Music and Memory Program that brought clinicians and nursing home staff together. The goal was to help support innovative ways to address dementia without the use of antipsychotics.

All of our partners supported the initiatives and continued to sustain that support. We also participate on CMS webinars and make sure that all of our surveyors embrace this and the mandatory surveyor training. We believe that supporting many different options for improvement as well as ensuring appropriate enforcement, provides a holistic approach to reduction of antipsychotics.”

### Websites, Tools and Resources

Over the past two years, CMS and its partners developed numerous resources and made them available in the public domain. This work by government agencies, QIOs, professional associations, advocates and others greatly expanded educational offerings on dementia care and antipsychotic medication reduction available to all nursing homes, clinicians and consumers. In particular, resources targeting prescribers were produced and widely disseminated. (For examples of National, State and local programs offered as part of the initiative, see Appendix D).

- CMS supported AE leadership to establish and deploy a new webpage dedicated to the National Partnership (<http://www.nhqualitycampaign.org>). This website includes an extensive set of webpages specific to the National Partnership with detailed technical assistance, tools and educational resources all available for free and in the public domain. The website remains dynamic and new information is added on a regular basis. For example, in February 2014, a new package of materials specific to and developed by physicians was added ([http://www.nhqualitycampaign.org/files/Physician%20Package 2-13-14.PDF](http://www.nhqualitycampaign.org/files/Physician%20Package%202-13-14.PDF)).
- The Affordable Care Act directed CMS to develop training for nursing assistants on abuse prevention and dementia care. Hand-in-Hand, a series of six DVDs, was created and produced by CMS, along with a team of national dementia care practitioners and expert reviewers (including advocates and family members). This training program was distributed for free to every nursing home in the country. Feedback on national calls reflects that many nursing homes are using Hand-in-Hand to train staff, and QIOs and other groups are adapting the materials to meet the specific needs of individual organizations. <http://www.cms-handinhandtoolkit.info/Index.aspx> .

- A toolkit for nurses on how to effectively work with residents who manifest behaviors related to dementia was developed by a group of nurse researchers and expert clinicians through a grant from the Commonwealth Fund titled: Toolbox for Improving Behavioral Health in Nursing Homes Project (#20130170). This toolkit includes a systematic, comprehensive, evidence-based approach to assessment of individuals with dementia, and also an approach to organizational systems and processes that will support safe and effective dementia care in nursing homes. The toolkit, now titled: Promoting Positive Behavioral Health: A Non-pharmacological Toolkit for Senior Living Communities may be accessed at <http://www.nursinghometoolkit.com>, and includes specific non-pharmacological interventions, assessment tools, approaches to staff training, and a review of the evidence with links to scholarly papers and other resources. There are plans for wide dissemination of this toolkit through the QIOs, AE, professional associations and government agencies. Researchers also plan to evaluate the effectiveness of toolkit dissemination and whether practice actually changes as a result.

### Public Reporting

- CMS began public reporting of incidence (short-stay residents) and prevalence (long-stay residents) of antipsychotic medication use for each nursing home on Nursing Home Compare (NHC) beginning in July, 2012. The long-stay prevalence measure on NHC is used to track the progress of the CMS National Partnership. CMS used data from the last three quarters of Calendar Year 2011 as a baseline. The national average for the percentage of long-stay residents who received an antipsychotic during this time period was 23.8%. (See Figures 1-6, pgs. 21-26).  
In addition, CMS sends quarterly updates with State and National averages and rates for each facility in the State to the State Coalition leads, as well as many professional associations who then share the reports with their State Chapter leadership. This enabled CMS and its partners to track improvement at the State level, as well as to identify facilities with persistently high rates and little or no change. Beginning in 2013, CMS and State Coalitions increased direct outreach to those homes in several States. Data analysis on the progress of the homes that received direct outreach is underway.

### CMS Surveyor Guidance Updates, Surveyor Training, and Enforcement

- All facilities, but particularly those with high antipsychotic prevalence rates in people with dementia must be closely examined during the survey process. In order to facilitate this increased scrutiny, CMS implemented enhanced guidance for State surveyors in Appendix PP of the State Operations Manual and notified States of the guidance changes via <http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-13-35.pdf>. The purpose of these revisions was to improve surveyors' ability to detect deficient practices related to dementia care and unnecessary antipsychotic medication use, and to ensure that residents with dementia who are receiving an antipsychotic medication are

evaluated on all standard surveys. The revisions included more detailed guidance on §483.25 Quality of Care, Care and Services of a Resident with Dementia, F tag 309; and revisions/clarifications to §483.25(l) Unnecessary Medications, F 329. S&C 13-35-NH specifically addresses the issue of antipsychotic medication use in dementia:

*It has been a common practice to use various types of psychopharmacological medications in nursing homes to try to address behaviors without first determining whether there is a medical, physical, functional, psychological, emotional, psychiatric, social or environmental cause of the behaviors. Medications may be effective when they are used appropriately to address significant, specific underlying medical or psychiatric causes, or new or worsening behavioral symptoms. However, medications may be ineffective and are likely to cause harm if given without a clinical indication. All interventions, including medications, need to be monitored for efficacy, risks, benefits and harm. The problematic use of medications, such as antipsychotics, is part of a larger, growing concern. This concern is that nursing homes and other settings (i.e. hospitals, ambulatory care) may use medications as a “quick fix” for behavioral symptoms or as a substitute for a holistic approach that involves a thorough assessment of underlying causes of behaviors and individualized, person-centered interventions.*

- CMS produced a series of three mandatory training programs for all State surveyors (2012-2013). These training videos are also available to the public and may be accessed at <http://surveyortraining.cms.hhs.gov/pubs/AntiPsychoticMedHome.aspx>.
  - The first program provides an overview of the use of antipsychotic medications in people with dementia, the risks and benefits, and evidence for when to use such medications and when to avoid them.
  - The second program is interactive, and walks surveyors through the actual process of surveying for F309, Care and Services for a Resident with Dementia and F329, Unnecessary Drugs. The surveyor views a vignette and enters his or her response to the situation and whether or not a deficiency exists. There is then discussion on the video and teaching points are summarized.
  - The third video presents a number of case studies on scope and severity, guiding surveyors through the process of how to cite a deficient practice at F309 and F329, and particularly how to determine whether actual harm exists and can be associated with a particular deficient practice at one of these tags.

To date, 75% of surveyors nationally completed the training and the remainder have been scheduled.

In 2014, CMS began quarterly calls with regional office and survey agency leaders to address enforcement issues, discuss additional training needs and surveyor feedback on the new guidance.

## Research

A number of research initiatives related to dementia care and antipsychotic use were already underway in 2011, and more were funded or expanded as part of the National Partnership. An international group of researchers convened by Dr. Linda Simoni-Wastila from the University of Maryland, Baltimore held regular conference calls over the past two years, to share new findings and learn about one another's studies. Some current areas of research include: health services research such as analyses of pharmacy, minimum data set (MDS) and claims data (New Jersey, Maryland); application of prescription monitoring program (PMP) data to expanded clinical use and use in the regulatory process (Illinois); and studies with nursing home staff on implementation of non-pharmacological approaches to dementia care (Massachusetts, Michigan).

- CMS contracted with Health Management Solutions (HMS) and researchers at the University of Massachusetts Medical School Meyers Primary Care Institute to conduct a descriptive study in order to better understand the reasons for use of antipsychotic medications in nursing home residents with dementia. The team gathered data from a sample of 204 NH residents with dementia in 25 medium and large-sized facilities located in five selected CMS regions. Reasons for antipsychotic use given by interviewees or noted in the medical record for the 204 nursing home residents in the study sample fell into four categories: behavioral, psychiatric, emotional states and cognitive symptoms. In this sample, the rationale for use of antipsychotic drug therapy frequently related to symptoms for which these drugs are not approved (e.g., “crying” or “problems with daily care”) and for which evidence of efficacy is lacking. A manuscript is under review.
- The Commonwealth Fund sponsored a study by the Center for Medicare Advocacy and Dean Lerner Consulting in which reviewers examined annual and complaint survey inspection reports from seven States. Specifically, they reviewed the scope and severity of 295 citations at F329 in which antipsychotic medications were identified as unnecessary drugs. The reviewers also conducted focus groups with State survey directors and distributed an online survey to over 500 surveyors in 10 States that asked State surveyors about their attitudes and perceptions of how surveyors cite or do not cite nursing homes for deficient practices related to dementia care or antipsychotic medication use. Preliminary findings suggest that surveyors believe it can be difficult to identify, cite and enforce deficient practice related to antipsychotic medication use. Surveyors commented that the process of conducting a detailed investigation can be time consuming, but they believe it is important. CMS and the authors continue to discuss initial findings and recommendations from this study.

<http://www.medicareadvocacy.org/cma-report-examining-inappropriate-use-of-antipsychotic-drugs-in-nursing-facilities/>

- A project to develop and test an integrated, clinical database using data from the minimum data set (MDS) and the prescription monitoring program (PMP) in Illinois is currently underway. This will provide surveyors with additional clinical and pharmacy data on nursing home residents related to psychopharmacological use in people with dementia prior to beginning each survey.

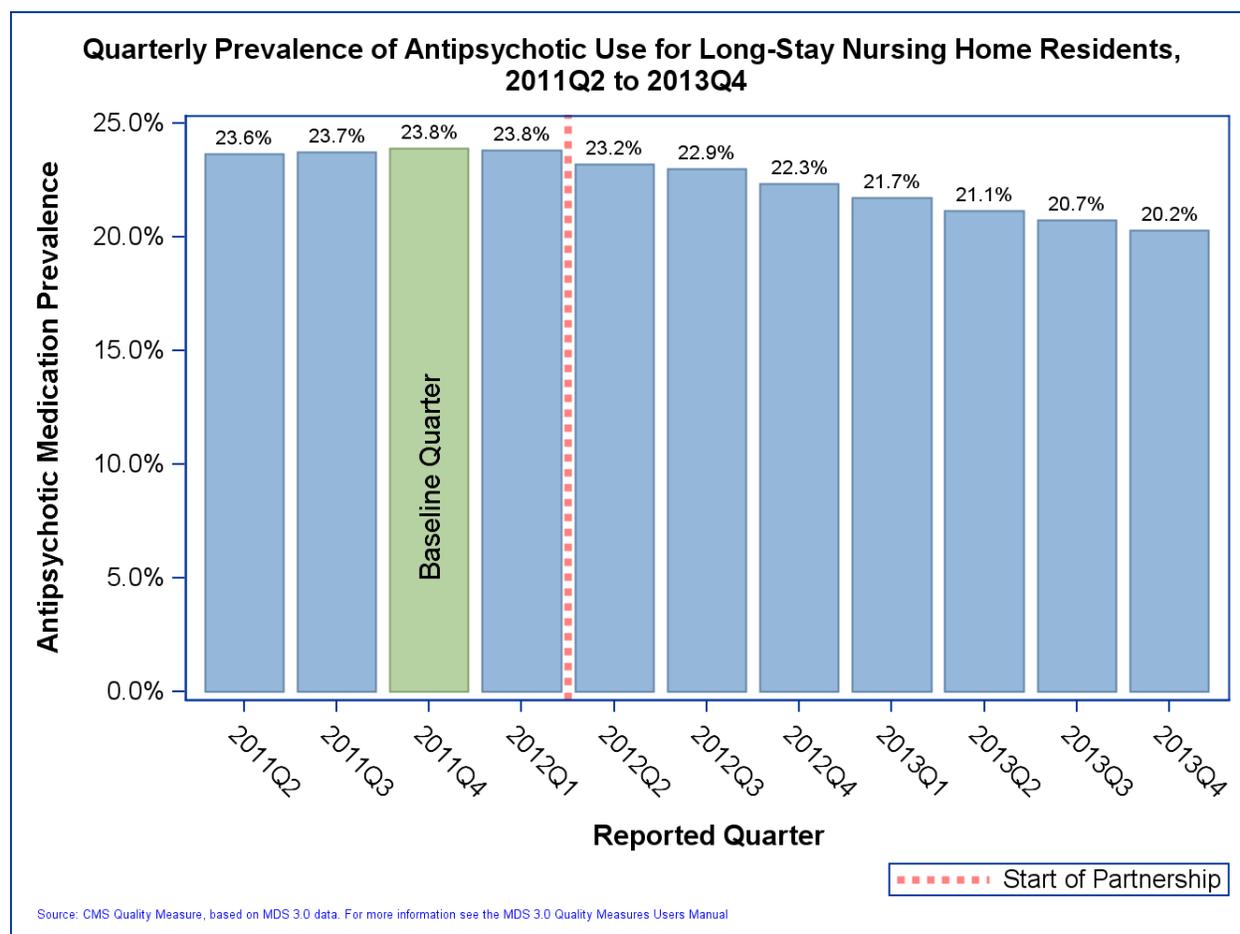
## Current Data Trends

- Over 18 months, the national prevalence of antipsychotic use in long-stay NH residents was reduced by 15.1% (the rate decreased from 23.8% to 20.2%) and every CMS region showed at least some improvement (Figures 1-2, pgs. 21-22). Some States showed much more improvement than others (Figure 3, pg. 23); for example, Georgia reduced their rate by 26.4% and North Carolina saw a 27.1% reduction. Baseline rates varied widely among States and Regions; studies are underway to determine which States improved most rapidly to describe the characteristics/infrastructure of those State Coalitions and partner organizations. Incidence in short-stay residents showed improvement as well.
- Deficiency citation trends for F329 from 2009-2013 are presented in Tables 1-4 and Figure 7, pgs. 27-29. CMS will continue to track citation patterns by State and Region at F329, including scope and severity. (It should be noted that not all citations at F329 relate to antipsychotic medications specifically; this tag includes deficiencies related to any unnecessary drug).
- CMS reviewed mental/neurological diagnoses (Table 5, p. 30) and rates of use for other psychopharmacologicals, such as anxiolytics and sedative/hypnotics (Table 6, p. 30). Data as of 3/2014 suggest a slight increase in the percentage of nursing home residents who were coded on the MDS as having schizophrenia, and a small decline in the use of sedative-hypnotics, as well as a significant reduction in antipsychotics during the initiative.

## Figure 1: Quarterly Prevalence of Antipsychotic Use for Long-Stay Nursing Home Residents, 2011Q2 to 2013Q4

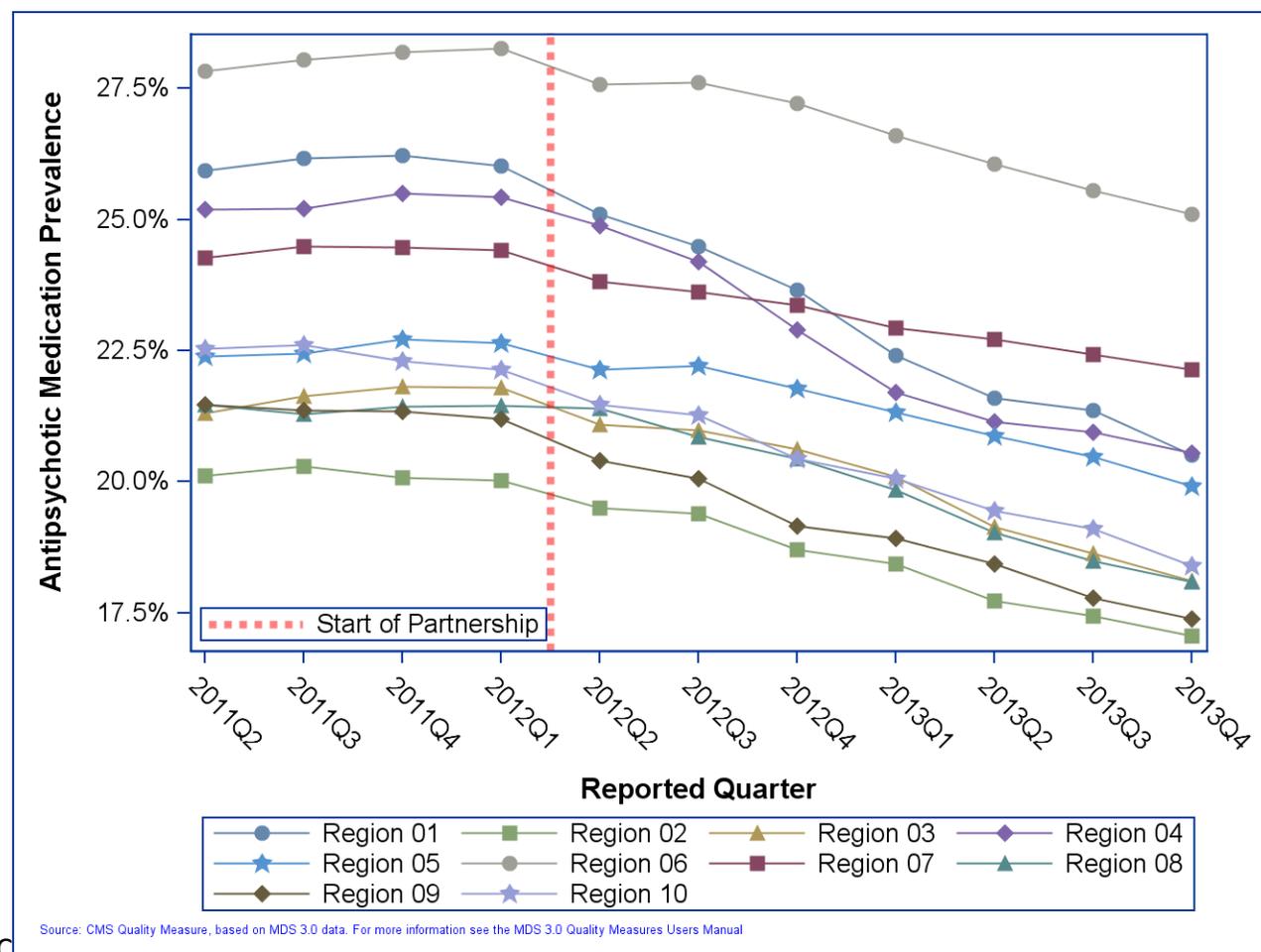
The official measure of the Partnership is the percent of long-stay nursing home residents who are receiving an antipsychotic medication, excluding those residents diagnosed with schizophrenia, Huntington's Disease or Tourette's Syndrome.

A three-quarter measure is posted to the Nursing Home Compare website at [www.medicare.gov/nursinghomecompare](http://www.medicare.gov/nursinghomecompare). The long-stay measure on Nursing Home Compare, is the exact same measure as below, except each facility's score is averaged over the last three quarters in order to give consumers information on the past history of each facility.



**Figure 2: Quarterly Prevalence of Antipsychotic Use for Long-Stay Residents, CMS Regions 2011Q2 to 2013Q4**

CMS Region- and State-specific data are displayed below. These data show the change in the single-quarter prevalence of antipsychotic medication use amongst long-stay residents since 2011Q2 and shows the change since the start of the Partnership.



C

Region	2011Q2	2011Q3	2011Q4	2012Q1	2012Q2	2012Q3	2012Q4	2013Q1	2013Q2	2013Q3	2013Q4	Percentage point difference (2011Q4-2013Q4)	Percent change
National	23.6%	23.7%	23.9%	23.8%	23.2%	23.0%	22.3%	21.7%	21.1%	20.8%	20.3%	-3.60	-15.1%
Region 01	25.9%	26.2%	26.2%	26.0%	25.1%	24.5%	23.7%	22.4%	21.6%	21.4%	20.5%	-5.71	-21.8%
Region 02	20.1%	20.3%	20.1%	20.0%	19.5%	19.4%	18.7%	18.4%	17.7%	17.4%	17.1%	-3.02	-15.0%
Region 03	21.3%	21.6%	21.8%	21.8%	21.1%	21.0%	20.6%	20.1%	19.1%	18.6%	18.1%	-3.71	-17.0%
Region 04	25.2%	25.2%	25.5%	25.4%	24.9%	24.2%	22.9%	21.7%	21.1%	20.9%	20.5%	-4.97	-19.5%
Region 05	22.4%	22.5%	22.7%	22.7%	22.1%	22.2%	21.8%	21.3%	20.9%	20.5%	19.9%	-2.80	-12.3%
Region 06	27.8%	28.1%	28.2%	28.3%	27.6%	27.6%	27.2%	26.6%	26.1%	25.6%	25.1%	-3.09	-11.0%
Region 07	24.3%	24.5%	24.5%	24.4%	23.8%	23.6%	23.4%	22.9%	22.7%	22.4%	22.1%	-2.34	-9.5%
Region 08	21.5%	21.3%	21.4%	21.5%	21.4%	20.9%	20.4%	19.8%	19.0%	18.5%	18.1%	-3.35	-15.6%
Region 09	21.5%	21.4%	21.3%	21.2%	20.4%	20.1%	19.2%	18.9%	18.4%	17.8%	17.4%	-3.94	-18.5%
Region 10	22.5%	22.6%	22.3%	22.1%	21.5%	21.3%	20.4%	20.1%	19.5%	19.1%	18.4%	-3.89	-17.5%

Source: CMS Quality Measure, based on MDS 3.0 data. For more information see the MDS 3.0 Quality Measures Users Manual

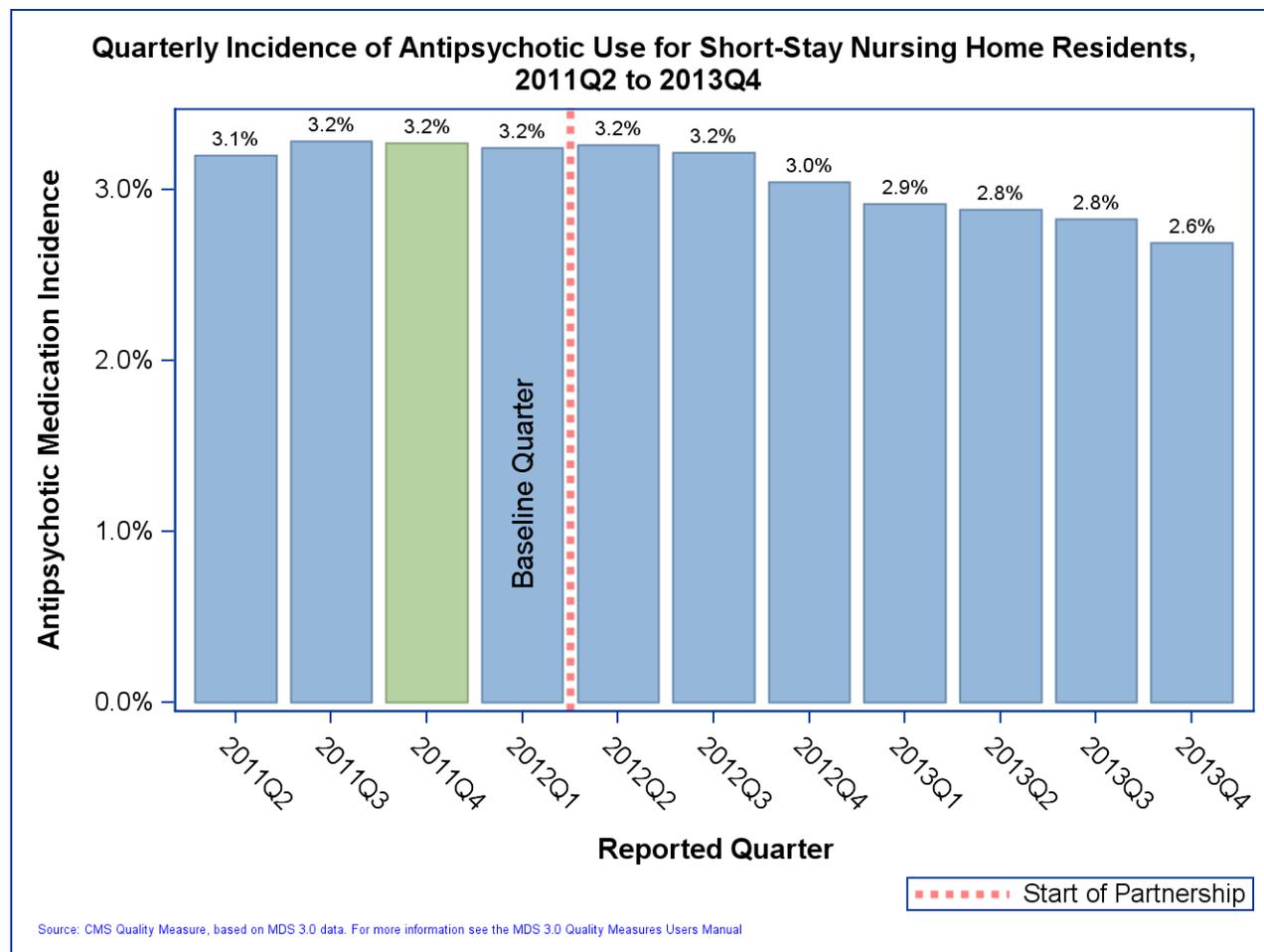
**Figure 3: Quarterly Prevalence of Antipsychotic Use for Long-Stay Residents, States 2011Q2 to 2013Q4**

State	2011Q2	2011Q3	2011Q4	2012Q1	2012Q2	2012Q3	2012Q4	2013Q1	2013Q2	2013Q3	2013Q4	Rank in 2013Q4 (lower=better)	Percentage point difference (2011Q4-2013Q4)	Percent change
ALABAMA	27.0%	27.4%	27.3%	27.5%	26.5%	26.0%	24.0%	22.9%	22.2%	22.3%	22.2%	42	-5.13	-18.8%
ALASKA	15.6%	15.1%	13.7%	13.4%	13.0%	13.6%	12.4%	12.5%	11.8%	15.0%	12.8%	2	-0.89	-6.5%
ARIZONA	22.4%	22.5%	22.7%	22.7%	21.7%	21.6%	20.9%	20.4%	20.2%	19.9%	20.7%	33	-2.07	-9.1%
ARKANSAS	25.7%	27.0%	26.1%	26.1%	25.3%	25.8%	25.5%	25.1%	24.4%	23.8%	22.8%	44	-3.28	-12.6%
CALIFORNIA	21.7%	21.6%	21.6%	21.3%	20.4%	20.1%	19.2%	19.0%	18.4%	17.7%	17.1%	14	-4.46	-20.7%
COLORADO	19.8%	19.7%	19.9%	19.9%	20.3%	19.6%	19.4%	18.5%	17.5%	17.0%	16.4%	11	-3.48	-17.5%
CONNECTICUT	25.8%	26.1%	26.0%	25.8%	25.0%	24.3%	23.2%	22.4%	21.6%	22.0%	21.0%	34	-5.09	-19.5%
DELAWARE	21.1%	21.0%	21.3%	21.8%	22.6%	21.9%	20.9%	18.0%	16.8%	16.8%	15.5%	7	-5.76	-27.0%
DISTRICT OF COLUMBIA	21.4%	20.0%	20.0%	19.4%	18.8%	19.4%	18.2%	17.4%	17.6%	15.9%	14.5%	4	-5.48	-27.4%
FLORIDA	24.2%	24.3%	24.5%	24.6%	23.8%	23.8%	23.3%	22.7%	22.1%	21.8%	21.2%	37	-3.26	-13.3%
GEORGIA	28.4%	28.4%	28.7%	28.7%	28.0%	27.1%	24.2%	22.7%	21.8%	21.4%	21.1%	35	-7.56	-26.4%
HAWAII	11.4%	12.2%	12.5%	13.5%	15.3%	13.2%	11.7%	11.0%	11.4%	12.1%	11.6%	1	-0.87	-7.0%
IDAHO	26.4%	25.7%	25.3%	26.4%	25.1%	24.5%	23.9%	23.1%	21.9%	20.7%	19.3%	26	-6.07	-24.0%
ILLINOIS	26.0%	25.8%	25.7%	25.6%	25.3%	25.7%	25.5%	25.0%	25.2%	24.8%	24.0%	48	-1.68	-6.5%
INDIANA	23.0%	23.6%	24.0%	24.1%	22.9%	23.1%	22.2%	21.7%	20.9%	21.0%	20.2%	32	-3.79	-15.8%
IOWA	22.2%	22.3%	22.3%	22.0%	21.7%	21.1%	20.6%	20.2%	20.2%	19.9%	20.0%	29	-2.31	-10.3%
KANSAS	26.1%	26.5%	26.1%	26.1%	25.2%	25.3%	25.1%	24.2%	23.9%	23.5%	23.0%	45	-3.12	-11.9%
KENTUCKY	25.5%	25.2%	26.0%	26.0%	25.2%	24.4%	23.1%	21.9%	22.0%	21.8%	21.6%	38	-4.38	-16.8%
LOUISIANA	29.7%	29.9%	29.7%	29.7%	29.1%	28.9%	28.6%	27.8%	27.0%	26.6%	26.5%	50	-3.24	-10.9%
MAINE	26.4%	26.7%	27.2%	26.9%	25.9%	25.1%	24.2%	22.6%	21.7%	21.3%	20.1%	30	-7.11	-26.1%
MARYLAND	19.5%	19.8%	19.8%	19.6%	18.5%	17.8%	17.7%	17.3%	16.7%	15.6%	15.9%	9	-3.92	-19.8%
MASSACHUSETTS	26.6%	26.7%	26.7%	26.6%	25.4%	25.1%	24.5%	22.9%	22.2%	21.8%	21.2%	36	-5.51	-20.6%
MICHIGAN	16.2%	16.0%	16.4%	16.4%	15.8%	16.0%	15.5%	14.9%	14.4%	14.1%	13.9%	3	-2.45	-15.0%
MINNESOTA	18.9%	19.0%	19.0%	18.8%	18.1%	18.0%	18.0%	17.9%	17.3%	16.7%	16.6%	13	-2.48	-13.0%
MISSISSIPPI	26.6%	26.8%	26.6%	26.3%	26.6%	26.1%	25.3%	24.7%	24.4%	25.3%	24.3%	49	-2.32	-8.7%
MISSOURI	25.5%	26.0%	26.1%	26.0%	25.3%	25.2%	24.9%	24.6%	24.4%	23.7%	23.1%	46	-3.02	-11.6%
MONTANA	21.6%	22.0%	21.5%	21.5%	19.5%	19.7%	19.5%	19.7%	19.2%	18.1%	17.2%	15	-4.28	-19.9%
NEBRASKA	22.7%	22.4%	22.3%	22.9%	22.6%	22.6%	22.9%	22.5%	22.2%	22.8%	22.7%	43	0.40	1.8%
NEVADA	22.2%	20.7%	20.3%	20.5%	21.1%	19.7%	20.2%	20.1%	20.4%	19.9%	19.7%	28	-0.55	-2.7%
NEW HAMPSHIRE	25.7%	25.4%	25.5%	25.1%	24.0%	23.8%	23.7%	22.7%	21.1%	21.2%	20.1%	31	-5.40	-21.2%
NEW JERSEY	17.0%	18.2%	17.9%	17.8%	17.5%	17.4%	17.1%	16.6%	15.9%	15.4%	15.1%	5	-2.80	-15.6%
NEW MEXICO	22.4%	22.3%	21.7%	22.0%	20.0%	20.4%	22.2%	20.3%	20.7%	17.7%	18.1%	18	-3.57	-16.5%
NEW YORK	22.0%	21.6%	21.3%	21.4%	20.8%	20.6%	19.7%	19.5%	18.9%	18.7%	18.2%	19	-3.10	-14.6%
NORTH CAROLINA	21.1%	20.8%	21.4%	21.3%	20.7%	19.9%	18.0%	16.5%	16.0%	15.8%	15.6%	8	-5.81	-27.1%
NORTH DAKOTA	20.8%	21.4%	21.3%	21.2%	20.6%	20.4%	19.8%	19.1%	18.5%	18.3%	18.7%	23	-2.61	-12.3%
OHIO	24.9%	25.0%	25.4%	25.4%	25.0%	24.8%	24.5%	24.1%	23.3%	22.7%	22.0%	41	-3.40	-13.4%
OKLAHOMA	26.7%	26.8%	27.3%	27.5%	27.3%	26.6%	25.5%	23.0%	22.7%	22.3%	21.7%	40	-5.59	-20.5%
OREGON	20.6%	21.0%	21.5%	21.3%	20.0%	19.9%	19.2%	19.1%	18.6%	18.8%	18.3%	20	-3.20	-14.9%
PENNSYLVANIA	21.6%	22.1%	22.3%	22.2%	21.7%	21.7%	21.1%	20.5%	19.4%	19.2%	18.8%	24	-3.54	-15.9%
RHODE ISLAND	23.0%	23.8%	24.0%	23.9%	23.1%	21.7%	20.2%	20.3%	19.3%	18.4%	17.5%	16	-6.49	-27.0%
SOUTH CAROLINA	20.6%	20.5%	20.7%	20.6%	20.7%	20.2%	18.3%	17.2%	16.9%	15.9%	15.5%	6	-5.23	-25.3%
SOUTH DAKOTA	21.8%	21.8%	21.5%	21.5%	21.3%	21.4%	20.5%	20.0%	18.8%	18.1%	18.6%	21	-2.95	-13.7%
TENNESSEE	29.3%	29.5%	30.0%	29.3%	29.0%	27.7%	27.2%	25.0%	23.9%	24.0%	23.4%	47	-6.58	-22.0%
TEXAS	28.4%	28.5%	28.8%	28.9%	28.2%	28.3%	28.0%	27.9%	27.3%	27.0%	26.5%	51	-2.35	-8.1%
UTAH	26.9%	24.7%	27.1%	26.9%	27.1%	26.3%	26.4%	25.0%	24.5%	23.6%	21.7%	39	-5.45	-20.1%
VERMONT	25.5%	26.1%	25.4%	25.7%	26.2%	24.9%	23.4%	20.3%	20.2%	20.2%	18.8%	25	-6.57	-25.9%
VIRGINIA	22.4%	22.8%	23.0%	22.9%	21.8%	21.9%	22.1%	22.1%	21.0%	20.5%	19.7%	27	-3.39	-14.7%
WASHINGTON	22.8%	23.0%	22.3%	21.8%	21.7%	21.6%	20.6%	20.2%	19.7%	19.1%	18.6%	22	-3.71	-16.6%
WEST VIRGINIA	20.1%	20.3%	20.5%	21.5%	20.4%	20.7%	20.4%	19.8%	19.0%	18.0%	16.5%	12	-4.00	-19.5%
WISCONSIN	18.7%	18.7%	19.0%	18.9%	18.9%	19.0%	18.0%	17.7%	17.4%	16.8%	16.3%	10	-2.76	-14.5%
WYOMING	17.8%	18.4%	16.8%	16.9%	19.4%	16.8%	17.5%	17.0%	16.5%	17.2%	17.9%	17	1.11	6.6%

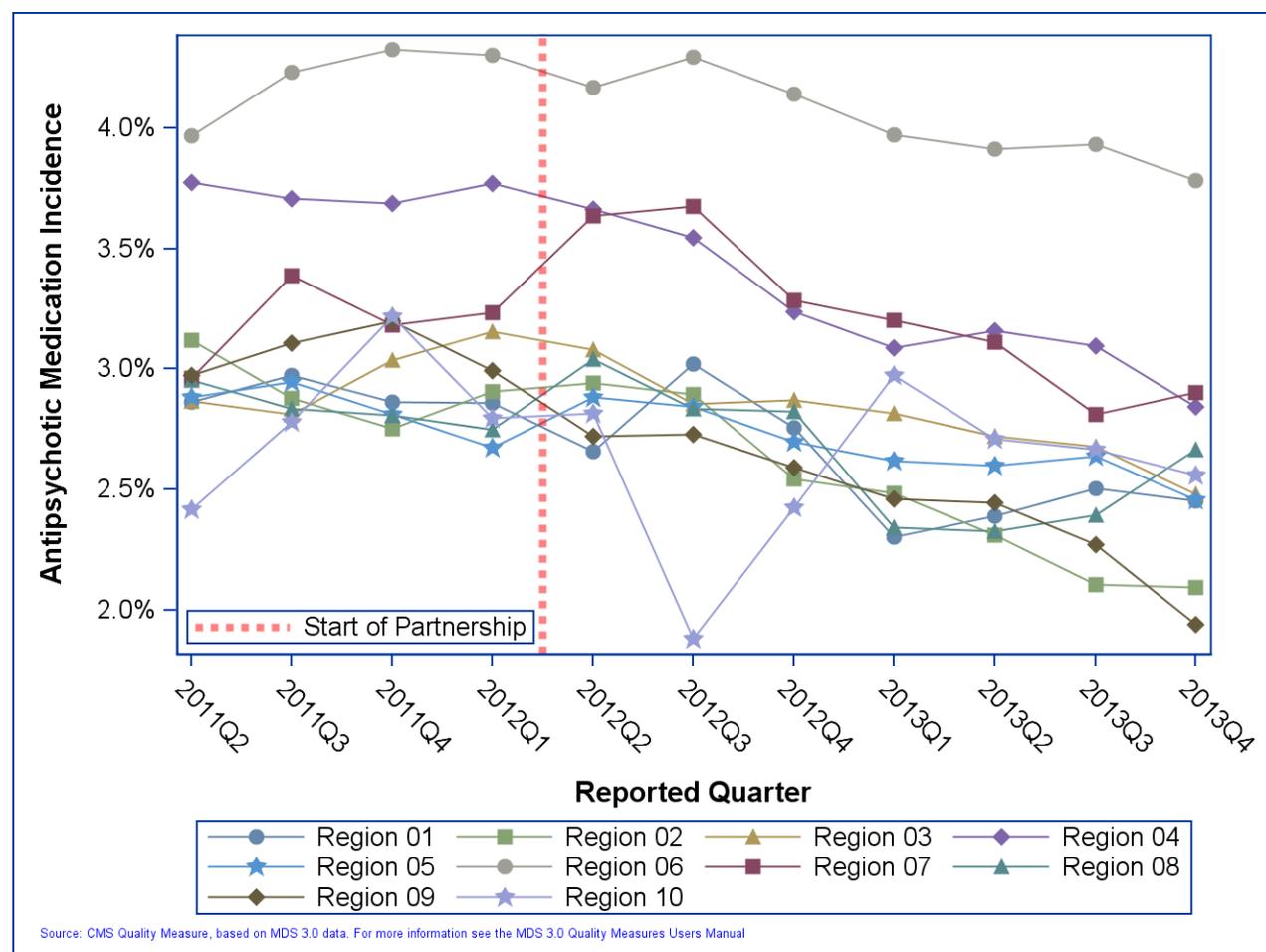
Source: CMS Quality Measure, based on MDS 3.0 data. For more information see the MDS 3.0 Quality Measures Users Manual

**Figure 4: Quarterly Incidence of Antipsychotic Use for Short-Stay Nursing Home Residents, 2011Q2-2013Q4**

CMS is tracking the progress of the Partnership by reviewing publicly reported measures. The official measure of the Partnership is a the percent of long-stay nursing home residents who are receiving an antipsychotic medication, excluding those residents diagnosed with schizophrenia, Huntington's Disease or Tourette's Syndrome (see Figures 1-3).



**Figure 5: Quarterly Incidence of Antipsychotic Use for Short-Stay Residents, CMS Regions 2011Q2 to 2013Q4**



Region	2011Q1	2011Q2	2011Q3	2011Q4	2012Q1	2012Q2	2012Q3	2012Q4	2013Q1	2013Q2	2013Q3	2013Q4	Percentage point difference (2011Q4-2013Q4)	Percent change
National	3.2%	3.2%	3.3%	3.3%	3.2%	3.3%	3.2%	3.0%	2.9%	2.9%	2.8%	2.7%	-0.58	-17.7%
Region 01	3.1%	2.9%	3.0%	2.9%	2.9%	2.7%	3.0%	2.8%	2.3%	2.4%	2.5%	2.5%	-0.41	-14.4%
Region 02	2.9%	3.1%	2.9%	2.8%	2.9%	2.9%	2.9%	2.5%	2.5%	2.3%	2.1%	2.1%	-0.66	-23.8%
Region 03	2.9%	2.9%	2.8%	3.0%	3.2%	3.1%	2.9%	2.9%	2.8%	2.7%	2.7%	2.5%	-0.56	-18.3%
Region 04	3.9%	3.8%	3.7%	3.7%	3.8%	3.7%	3.5%	3.2%	3.1%	3.2%	3.1%	2.8%	-0.84	-22.9%
Region 05	2.9%	2.9%	2.9%	2.8%	2.7%	2.9%	2.8%	2.7%	2.6%	2.6%	2.6%	2.5%	-0.35	-12.6%
Region 06	4.2%	4.0%	4.2%	4.3%	4.3%	4.2%	4.3%	4.1%	4.0%	3.9%	3.9%	3.8%	-0.55	-12.6%
Region 07	2.9%	3.0%	3.4%	3.2%	3.2%	3.6%	3.7%	3.3%	3.2%	3.1%	2.8%	2.9%	-0.28	-8.9%
Region 08	3.0%	3.0%	2.8%	2.8%	2.8%	3.0%	2.8%	2.8%	2.3%	2.3%	2.4%	2.7%	-0.14	-5.0%
Region 09	2.8%	3.0%	3.1%	3.2%	3.0%	2.7%	2.7%	2.6%	2.5%	2.4%	2.3%	1.9%	-1.26	-39.3%
Region 10	2.6%	2.4%	2.8%	3.2%	2.8%	2.8%	1.9%	2.4%	3.0%	2.7%	2.7%	2.6%	-0.66	-20.4%

Source: CMS Quality Measure, based on MDS 3.0 data. For more information see the MDS 3.0 Quality Measures Users Manual

**Figure 6: Quarterly Incidence of Antipsychotic Use for Short-Stay Residents, States 2011Q2 to 2013Q4**

State	2011Q2	2011Q3	2011Q4	2012Q1	2012Q2	2012Q3	2012Q4	2013Q1	2013Q2	2013Q3	2013Q4	Rank in 2013Q4 (lower=better)	Percentage point difference (2011Q4- 2013Q4)	Percent change
ALABAMA	3.4%	3.1%	3.5%	3.4%	3.6%	3.1%	2.7%	2.7%	2.7%	3.7%	3.1%	41	-0.35	-10.0%
ALASKA	2.2%	1.0%	1.0%	11.4%	0.2%	1.4%	0.8%	0.3%	0.3%	6.9%	10.2%	51	9.24	915.7%
ARIZONA	3.2%	3.1%	2.8%	2.2%	2.1%	2.2%	2.4%	2.6%	2.3%	1.9%	1.8%	8	-0.97	-34.8%
ARKANSAS	4.2%	4.8%	3.8%	3.5%	3.6%	4.0%	4.5%	4.0%	4.0%	3.9%	3.1%	42	-0.61	-16.3%
CALIFORNIA	2.9%	3.1%	3.2%	3.1%	2.8%	2.8%	2.6%	2.5%	2.5%	2.3%	1.9%	12	-1.29	-39.8%
COLORADO	2.8%	2.9%	2.8%	2.9%	2.8%	2.8%	2.1%	2.5%	2.5%	2.4%	2.8%	31	-0.02	-0.8%
CONNECTICUT	3.0%	3.5%	3.0%	3.0%	3.1%	2.6%	2.3%	2.8%	2.7%	2.3%	1.9%	11	-1.04	-35.0%
DELAWARE	2.8%	2.3%	3.7%	4.4%	3.9%	5.7%	2.3%	4.3%	2.8%	2.9%	2.2%	21	-1.50	-40.2%
DISTRICT OF COLUMBIA	3.9%	3.3%	3.6%	3.3%	3.5%	4.2%	4.0%	3.2%	3.4%	2.8%	2.1%	16	-1.49	-41.3%
FLORIDA	3.6%	3.5%	3.5%	3.5%	3.6%	3.5%	3.5%	3.4%	3.3%	3.3%	3.2%	43	-0.33	-9.5%
GEORGIA	4.6%	4.4%	4.3%	4.7%	4.5%	4.3%	3.0%	3.3%	3.5%	3.3%	3.1%	39	-1.27	-29.3%
HAWAII	2.4%	1.4%	1.9%	2.0%	1.5%	1.8%	1.0%	1.0%	1.5%	1.5%	1.2%	1	-0.65	-34.2%
IDAHO	2.3%	3.4%	4.9%	4.3%	5.0%	2.0%	3.8%	6.0%	4.4%	2.1%	3.0%	38	-1.93	-39.5%
ILLINOIS	3.7%	3.7%	3.3%	3.2%	3.3%	3.8%	3.5%	3.6%	3.7%	3.3%	3.1%	40	-0.22	-6.7%
INDIANA	3.5%	3.9%	3.1%	3.2%	3.6%	2.9%	2.9%	2.8%	2.8%	2.9%	2.6%	28	-0.56	-17.9%
IOWA	2.7%	2.4%	2.7%	2.3%	2.8%	2.7%	2.5%	2.5%	2.4%	2.2%	2.5%	25	-0.23	-8.5%
KANSAS	3.3%	4.7%	4.0%	4.0%	4.4%	5.0%	3.8%	3.7%	4.4%	3.2%	4.0%	48	-0.03	-0.7%
KENTUCKY	3.7%	3.8%	3.9%	3.9%	4.0%	3.7%	3.2%	3.2%	3.4%	3.2%	2.9%	37	-0.99	-25.2%
LOUISIANA	4.5%	4.1%	4.8%	5.3%	4.3%	4.9%	4.6%	4.6%	4.2%	4.1%	4.1%	50	-0.71	-14.7%
MAINE	2.4%	2.3%	2.3%	3.4%	2.3%	2.7%	2.3%	2.2%	1.7%	1.9%	1.8%	9	-0.43	-19.1%
MARYLAND	3.0%	2.9%	2.9%	3.0%	3.2%	2.7%	2.7%	2.4%	2.4%	2.3%	2.3%	22	-0.59	-20.4%
MASSACHUSETTS	3.0%	2.9%	3.2%	2.9%	2.3%	3.3%	3.3%	2.2%	2.4%	2.7%	3.2%	45	0.01	0.3%
MICHIGAN	2.3%	2.4%	2.6%	2.2%	2.4%	2.1%	1.9%	1.9%	2.0%	2.0%	1.9%	13	-0.62	-24.2%
MINNESOTA	2.0%	2.1%	2.6%	2.0%	2.5%	2.4%	2.0%	1.8%	2.1%	2.2%	1.7%	4	-0.98	-37.1%
MISSISSIPPI	3.8%	3.9%	3.8%	3.7%	4.1%	4.5%	4.4%	3.6%	4.6%	3.4%	2.6%	27	-1.26	-33.1%
MISSOURI	3.2%	3.6%	3.4%	3.6%	3.6%	3.6%	3.5%	3.6%	3.1%	3.1%	2.9%	36	-0.45	-13.2%
MONTANA	3.4%	1.9%	3.6%	2.8%	3.1%	3.3%	4.8%	2.6%	2.2%	1.6%	2.8%	32	-0.85	-23.4%
NEBRASKA	2.4%	2.7%	2.6%	3.0%	4.3%	4.0%	3.5%	3.2%	2.8%	3.0%	2.2%	19	-0.39	-15.1%
NEVADA	4.1%	4.2%	4.7%	3.4%	3.6%	3.7%	3.1%	3.1%	2.9%	2.9%	2.6%	29	-2.06	-44.0%
NEW HAMPSHIRE	3.5%	3.2%	2.1%	1.8%	2.7%	2.1%	1.9%	2.0%	3.2%	2.4%	1.3%	2	-0.76	-37.3%
NEW JERSEY	2.6%	2.3%	2.2%	2.1%	1.9%	2.0%	1.9%	2.0%	1.9%	1.8%	1.7%	5	-0.46	-21.1%
NEW MEXICO	3.3%	2.6%	2.8%	3.7%	3.4%	3.7%	2.3%	3.8%	4.1%	2.7%	2.2%	20	-0.55	-20.0%
NEW YORK	3.4%	3.2%	3.1%	3.4%	3.6%	3.4%	2.9%	2.8%	2.6%	2.3%	2.3%	23	-0.77	-24.7%
NORTH CAROLINA	3.3%	2.9%	3.0%	3.0%	2.9%	2.8%	2.4%	2.3%	2.2%	2.4%	2.1%	17	-0.83	-28.1%
NORTH DAKOTA	3.4%	2.1%	2.3%	3.6%	2.6%	2.6%	2.3%	2.8%	2.3%	1.3%	2.8%	33	0.44	18.9%
OHIO	3.0%	2.9%	2.9%	2.8%	2.9%	3.0%	3.1%	2.9%	2.5%	2.9%	2.8%	34	-0.07	-2.3%
OKLAHOMA	4.0%	4.3%	4.1%	3.6%	3.8%	4.2%	3.2%	3.2%	4.0%	4.0%	3.4%	46	-0.76	-18.4%
OREGON	2.0%	2.5%	3.7%	2.5%	2.0%	1.5%	1.6%	1.9%	1.9%	2.3%	2.7%	30	-1.01	-27.2%
PENNSYLVANIA	2.9%	2.8%	3.0%	3.1%	2.9%	2.7%	2.7%	2.5%	2.6%	2.8%	2.6%	26	-0.50	-16.3%
RHODE ISLAND	2.1%	2.8%	2.4%	2.9%	3.7%	3.6%	2.9%	2.0%	2.5%	2.5%	2.0%	15	-0.45	-18.3%
SOUTH CAROLINA	3.0%	3.1%	3.3%	3.6%	2.9%	3.0%	2.8%	2.6%	2.6%	2.0%	2.2%	18	-1.10	-33.8%
SOUTH DAKOTA	3.2%	4.6%	3.4%	2.3%	3.3%	3.3%	3.3%	1.6%	1.9%	3.5%	1.8%	6	-1.60	-47.3%
TENNESSEE	4.7%	5.0%	4.5%	4.5%	3.9%	3.7%	4.0%	3.5%	3.4%	3.1%	3.2%	44	-1.31	-29.1%
TEXAS	3.8%	4.2%	4.5%	4.5%	4.4%	4.3%	4.3%	4.0%	3.8%	4.0%	4.0%	49	-0.44	-9.9%
UTAH	2.5%	2.1%	2.3%	2.8%	4.1%	2.8%	2.8%	2.5%	2.8%	3.1%	3.6%	47	1.28	55.6%
VERMONT	1.9%	2.8%	2.5%	2.2%	2.8%	4.2%	2.3%	1.4%	0.8%	2.9%	2.0%	14	-0.52	-20.8%
VIRGINIA	2.7%	2.7%	3.0%	2.9%	2.9%	3.0%	3.6%	3.8%	3.4%	2.4%	2.4%	24	-0.64	-21.3%
WASHINGTON	2.7%	2.8%	2.4%	2.1%	2.7%	2.1%	2.5%	2.8%	2.8%	2.9%	1.8%	10	-0.58	-24.0%
WEST VIRGINIA	2.8%	2.9%	3.0%	3.9%	3.8%	2.7%	2.3%	2.6%	2.3%	3.4%	2.8%	35	-0.15	-5.1%
WISCONSIN	1.9%	1.7%	1.8%	1.8%	2.2%	1.8%	1.5%	1.3%	1.7%	1.5%	1.6%	3	-0.14	-8.2%
WYOMING	2.1%	2.4%	1.7%	1.4%	1.6%	1.1%	2.1%	1.9%	2.0%	1.1%	1.8%	7	0.04	2.4%

Source: CMS Quality Measure, based on MDS 3.0 data. For more information see the MDS 3.0 Quality Measures Users Manual

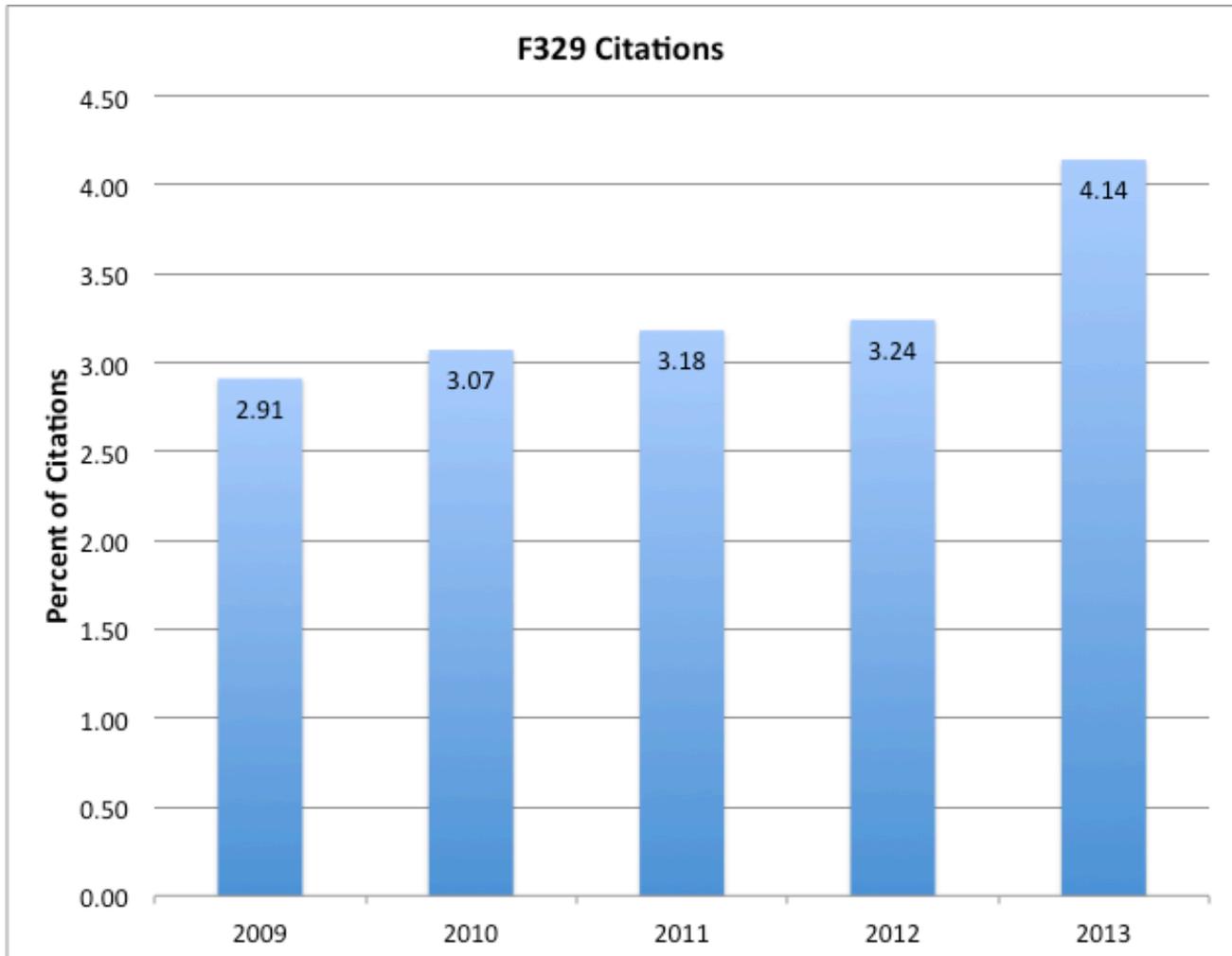
**Table 1. F329 Citations as a Percentage of All Citations on Annual Surveys, 2009-2013**

Region	2009 Citations on Annual Surveys		2010 Citations on Annual Surveys		2011 Citations on Annual Surveys		2012 Citations on Annual Surveys		2013 Citations on Annual Surveys	
	Percent F329 Citations	Total Citations								
1	2.75	5,124	3.11	4,471	3.38	3,902	3.46	3,994	4.17	3,788
2	2.39	5,183	2.37	4,857	2.91	5,129	2.94	4,871	3.23	4,639
3	2.78	9,196	3.35	7,705	2.73	7,998	3.49	8,162	4.83	8,403
4	2.70	13,175	2.43	12,272	2.69	11,117	2.66	10,989	2.61	9,930
5	3.70	22,274	3.88	20,645	4.08	21,264	4.28	19,060	5.64	17,976
6	2.33	13,695	2.07	12,575	2.14	13,019	1.78	12,900	2.82	13,036
7	2.44	10,755	3.17	9,494	3.31	9,496	3.42	8,411	4.46	8,288
8	2.95	4,543	3.31	4,508	3.25	3,815	3.69	4,497	4.12	4,540
9	2.80	13,765	2.82	13,703	2.94	12,295	2.85	12,277	3.98	11,996
10	4.14	2,996	4.95	3,029	4.95	3,213	5.19	2,716	5.25	2,762
<b>National</b>	<b>2.91</b>	<b>100,706</b>	<b>3.07</b>	<b>93,259</b>	<b>3.18</b>	<b>91,248</b>	<b>3.24</b>	<b>87,877</b>	<b>4.14</b>	<b>85,358</b>

**Table 2. Number of F329 and Total Citations on Annual Surveys, 2009-2013.**

Region	2009 Citations		2010 Citations		2011 Citations		2012 Citations		2013 Citations	
	F329 Citations	Total Citations								
1	141	5,124	139	4,471	132	3,902	138	3,994	158	3,788
2	124	5,183	115	4,857	149	5,129	143	4,871	150	4,639
3	256	9,196	258	7,705	218	7,998	285	8,162	406	8,403
4	356	13,175	298	12,272	299	11,117	292	10,989	259	9,930
5	825	22,274	802	20,645	868	21,264	815	19,060	1,014	17,976
6	319	13,695	260	12,575	278	13,019	229	12,900	368	13,036
7	262	10,755	301	9,494	314	9,496	288	8,411	370	8,288
8	134	4,543	149	4,508	124	3,815	166	4,497	187	4,540
9	386	13,765	387	13,703	361	12,295	350	12,277	478	11,996
10	124	2,996	150	3,029	159	3,213	141	2,716	145	2,762
<b>National</b>	<b>2,927</b>	<b>100,706</b>	<b>2,859</b>	<b>93,259</b>	<b>2,902</b>	<b>91,248</b>	<b>2,847</b>	<b>87,877</b>	<b>3,535</b>	<b>85,358</b>

Figure 7. F329 Citations as a Percentage of All Citations on Annual Surveys, 2009-2013



**Table 3. F329 Citations at Actual Harm (G Level or above) as a Percentage of All F329 Citations on Annual Surveys, 2009-2013.**

Region	2009		2010		2011		2012		2013	
	% G+	Total F329 Citations								
1	2.13	141	3.60	139	1.52	132	0.00	138	0.63	158
2	0.81	124	0.00	115	0.67	149	2.10	143	0.00	150
3	2.34	256	1.94	258	1.83	218	1.75	285	0.49	406
4	1.12	356	1.34	298	1.67	299	1.03	292	0.77	259
5	1.94	825	1.87	802	1.84	868	0.86	815	0.59	1,014
6	1.88	319	1.92	260	1.44	278	2.62	229	1.09	368
7	3.44	262	1.33	301	1.59	314	1.04	288	1.08	370
8	2.24	134	2.68	149	1.61	124	2.41	166	2.67	187
9	1.81	386	1.03	387	1.66	361	0.57	350	1.46	478
10	0.81	124	0.67	150	0.00	159	0.00	141	1.38	145
<b>National</b>	<b>1.91</b>	<b>2,927</b>	<b>1.64</b>	<b>2,859</b>	<b>1.55</b>	<b>2,902</b>	<b>1.16</b>	<b>2,847</b>	<b>0.93</b>	<b>3,535</b>

**Table 4. Number of F329 Citations at Actual Harm (G Level or above) and Total F329 Citations on Annual Surveys, 2009-2013**

Region	2009		2010		2011		2012		2013	
	# G+	Total F329 Citations								
1	3	141	5	139	2	132	0	138	1	158
2	1	124	0	115	1	149	3	143	0	150
3	6	256	5	258	4	218	5	285	2	406
4	4	356	4	298	5	299	3	292	2	259
5	16	825	15	802	16	868	7	815	6	1,014
6	6	319	5	260	4	278	6	229	4	368
7	9	262	4	301	5	314	3	288	4	370
8	3	134	4	149	2	124	4	166	5	187
9	7	386	4	387	6	361	2	350	7	478
10	1	124	1	150	0	159	0	141	2	145
<b>National</b>	<b>56</b>	<b>2,927</b>	<b>47</b>	<b>2,859</b>	<b>45</b>	<b>2,902</b>	<b>33</b>	<b>2,847</b>	<b>33</b>	<b>3,535</b>

**Table 5. Comparison of Mental/Neurological Diagnoses - Long Stay, 2011 Q4 vs 2013 Q4.**

Mental/Neurological Disorder	Target Quarter 2011 Q4		Target Quarter 2013 Q4	
	No. of Residents	% of Residents	No. of Residents	% of Residents
Alzheimer's Disease	192,167	17.52	176,898	16.68
Non-Alzheimer's dementia	515,120	46.95	492,391	46.44
Schizophrenia	80,091	7.30	84,962	8.01
Huntington's Disease	3,005	0.27	3,127	0.29
Tourette's Syndrome	257	0.02	279	0.03

Source: MDS data from 20140304

**Table 6. Comparison of Psychotropic Medication Use - Long Stay, 2011 Q4 vs 2013 Q4.**

Psychotropic Medication Use	Target Quarter 2011 Q4		Target Quarter 2013 Q4	
	No. of Residents	% of Residents	No. of Residents	% of Residents
Antipsychotic	313,052	28.32	267,626	25.24
Anxiolytic	238,478	21.58	224,714	21.2
Antidepressant	611,425	55.32	582,948	54.99
Sedative/Hypnotic	68,374	6.19	51,390	4.85

Source: MDS data from 20140304. Note: antipsychotic percentages differ from NHC because this is a point in time calculation and not a rolling average. Also, there are no exclusions based on psychiatric diagnosis.

## **Reasons for Early Progress of the National Partnership**

### **Initial Meeting with CMS Administrator and Nursing Home Advocates**

In late 2011, a group of advocates from several nursing home organizations met with CMS Administrator Donald Berwick and senior CMS leaders. The advocates expressed concern for the high rates of antipsychotic medication use in nursing homes and asked if CMS could do more to address this persistent threat to quality and safety. It was the strong voice of the advocates and their unwavering belief that better care could be achieved that motivated CMS to establish the National Partnership, catalyzed a broad range of activities by provider organizations and others, and ultimately led to the formation of coalitions to improve dementia care in every State.

### **Grassroots State-based Coalitions**

The CMS National Partnership convened broad-based, grass roots stakeholder groups in every State, dedicated to the goal of reducing unnecessary antipsychotic use and improving dementia care in every nursing home. By making the campaign about comprehensive, person-centered dementia care for each resident, the fundamental goal of eliminating all threats to resident dignity and quality of life resonated across providers, regulators, advocates, and others. While advocates argued that these requirements are already in OBRA87 and regulations are in place that should be enforced, the initiative built on those regulatory and enforcement principles and looked beyond the regulatory framework to create a compelling call to action to improve dementia care nationwide. Advocacy organizations continued to be a driving force behind the initiative; as active participants in the State Coalitions, they encouraged CMS and its partners to maintain a focus on enforcement as well as quality improvement.

### **Culture Change Framework: Input from Frontline Workers, Residents and Families**

The grassroots partnerships at the State level were effective in translating stories from the field, with a strong focus on leading with core values, obtaining input from frontline workers, residents and families with respect to systems changes. These stories (e.g., functional and cognitive improvements when people with dementia were taken off of antipsychotic medications) were shared on State, regional and national webinars and conference calls, through posting of stories and videos on various websites, storyboards at many State and National conferences and through direct peer-to-peer mentoring that occurred both within and across States and regions. CMS, the QIOs, advocacy organizations and professional associations focused on the vital role of certified nursing assistants (CNAs), activities professionals, therapists, social workers and many other direct care staff on the interdisciplinary team. The initiative stressed safety culture principles of communication, teamwork, getting to know the resident and sharing that information across disciplines and shifts. This includes everyone on the team, such as the pharmacist and primary care practitioner, even though they are not always in the facility; this content was included in

training materials and discussions over the two years. The fundamental culture change principles of person-centered care and listening to and learning from frontline workers and how to effect this transformation was a central campaign theme.

“The greatest improvement was made by merely paying attention to those residents with prescriptions for antipsychotics and reviewing them as clinicians on a regular basis. We hold a monthly QA meeting that is only 15 minutes long (very focused and efficient). We start with a list of residents on antipsychotics and ask three questions:

1. Why are they on the antipsychotic?
2. How long have they been on the antipsychotic?
3. Do they still need it?

This creates a different culture than the physician coming in and writing orders... they are asking staff ‘what do you think?’” --Medical Director, Georgia Nursing Home (Georgia achieved a 26.4% reduction in antipsychotic use)

### Quality Assurance Performance Improvement (QAPI) Principles

Over the past two years, the Partnership incorporated a Quality Assurance Performance Improvement (QAPI) framework as the larger context for the specific work on improving dementia care. The five elements of QAPI are:

1. Design and Scope
2. Leadership and Governance
3. Feedback, Data systems and Monitoring
4. Performance Improvement Projects (PIPs)
5. Systematic Analysis and Systemic Action.

In terms of Design and Scope and using a systems-based approach, the campaign worked to break down barriers between disciplines and to break down silos that existed across settings. For example, in many communities, cross-continuum teams of staff from hospitals, long term care facilities, home and community-based service organizations are getting to know one another better so that they may work more effectively in caring for people with dementia who transition from one setting and one set of care providers to another. This is essential, since the risk of medication errors during transitions is high.<sup>29</sup> This illustrates the broad design and scope of the partnership, encompassing teams and relationships beyond nursing homes and recognizing the role that families and community-based providers play in how we work with people who have dementia.

With respect to Leadership and Governance, presenters on national calls discussed principles of leadership engagement, such as the board, administrator and medical director being fully

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<sup>29</sup> Tjia, J., Gurwitz, JH, Briesacher, BA. (2012). Challenge of Changing Nursing Home Prescribing Culture. *The American Journal of Geriatric Pharmacotherapy*. 10(1): 37-46.

engaged in the work and providing resources to enable staff to learn and successfully implement person-centered approaches to care processes.

“We work with psychiatrists during the contracting process. We make it clear that if we contract with them, we expect them to use non-pharmacological interventions and help manage residents with dementia without drugs.” --Corporate Medical Director, multi-facility chain

Additional examples of leadership principles were provided on the CMS QAPI website, as well as the Advancing Excellence website (tools and resources), the QIO NHQCC change package and materials developed by many professional organizations. Thus public access educational and technical materials using a QAPI framework were aligned and made available as part of the Partnership.

In terms of Feedback, Data Systems and Monitoring, in addition to providing publicly reported data on NHC, the campaign developed additional tools for use in day-to-day quality improvement at the facility and State level. These enable nursing homes to track and trend their own data, and for States to benchmark improvement and assist facilities through the Advancing Excellence Local Area Networks for Excellence or LANES. In some cases, these were developed by professional associations, pharmacy vendors, Advancing Excellence or the QIOs. The QIOs and AE have been particularly focused on the QAPI principle of managing with data, sharing feedback about the data with frontline staff, residents and families, and continuous monitoring for improvement.

In terms of PIPs, one of the most significant changes noted during the National Partnership was that facilities are adopting a systematic approach to PIPs that focus on gradual dose reduction or GDRs. In many cases, facilities changed their practices to include a regular and systematic review by the IDT of all residents with dementia who are receiving an antipsychotic and systemic action including a specific plan to evaluate whether a GDR is indicated for each of those residents. While this is already an OBRA requirement, a renewed focus using tools and templates on how to institute these reviews, the involvement of the consultant pharmacist, nursing team, medical director or primary care practitioners and discussion of goals with family members led to more facilities engaging in Plan-Do-Study-Act (PDSA) cycles around this practice. Several posters at recent conferences described positive results, including evidence that prevalence rates were cut in half in some cases.<sup>30</sup> In addition, the authors and teams reported that in many cases, this was not difficult to achieve, and was able to be accomplished without significant increases in nursing staff.

*Sample framework from training materials provided by a New Hampshire nursing home that began initiative in 2012 with an antipsychotic rate of 24.14%, saw a reduction to 13.33% in 2013 and sustained a rate of 7-10% in 2014 (based on self-reported CASPER data):*

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<sup>30</sup> AMDA Poster Presentations 2014 Annual Meeting, February 27<sup>th</sup>, Nashville, Tennessee.

*Q = **Question** the reason for the behavior*

*U= **Understand** the reason for the behavior, learn to speak their language*

*A= **Alternatives** to medications*

*L= **Look** at the resident and assess them*

*I= **Initiate alternative** interventions*

*T= **TEAM**= involve and educate*

*Y= **Yes** for success in reduction and positive outcomes*

### **Promoting Standardization while Permitting Adaptation and Customization**

CMS, in partnership with many professional associations, advocates, researchers and clinical experts developed an extensive set of tools and resources, and made them available on an open access website (<http://www.nhqualitycampaign.org>). This site was updated regularly with new materials, often provided by various partners, such as universities, QIOs, ombudsman agencies and others. The dynamic nature of the website was an indication of the level of engagement of multiple organizations and individuals in many States and all Regions. Feedback about the tools led to revisions, making them even more useful and accessible to end users. In general, the tools provided standardized approaches to care of people with dementia and processes such as gradual dose reduction, but were intended for individual facilities and States to be able to customize the tools to meet the unique needs of each State or setting. For example, assisted living facilities in a number of States adapted some of the tools for use in that setting.

### **Outreach to Top Ten Multi-facility Nursing Home Chains**

CMS began inviting representatives from the ten largest nursing home chains to present data and an overview of their efforts to reduce antipsychotic medications and implement comprehensive dementia care practices as part of the initiative. To date, five organizations shared their corporate-wide strategies and goals with CMS. Entities that saw a significant reduction in rates of antipsychotic use attribute this to several strategies, including:

- Direct outreach to facilities or prescribers with high use rates by the corporate medical director, chief nursing officer or director of pharmacy services
- Direct outreach to psychiatrists to clarify their role as valued members of the behavioral health team and set an expectation that their role goes beyond medication prescriber
- Convening multiple facilities to hear from peers about best practices in homes with particularly low use rates
- Enhancing relationship with acute care providers so that fewer patients are transferred to nursing homes on antipsychotic medications unless there is a clear clinical indication (working to discontinue medication prior to transfer)
- Educating families on the risks and benefits of antipsychotic medications so that they are truly informed
- Leveraging recreational therapy/activities, rehabilitation and other staff and moving staff around on various shifts to appropriately allocate staff to meet the needs of the residents.

### **State-based Pay-for-Performance Programs**

A number of States have pay-for-performance or value-based purchasing (VBP) through their Medicaid or managed Medicaid programs. For example, in Oklahoma there are State financial incentives for facilities that demonstrate enhanced person-centered care practices. The State Coalition leads believe that this focus on individualized care practices enabled them to achieve the 20.5% reduction in antipsychotic medication use in Oklahoma.

### **Enforcement and Regulatory Consistency**

CMS maintained a focus on regulatory consistency and enforcement since the beginning of the National Partnership. Expert frontline surveyors, survey agency and regional office leaders and advocates provided input on all aspects of the initiative since its inception. While many States saw improvement in their rates of antipsychotic use, certain regions of the country continue to experience higher rates than others (see Figures 2 and 3, Pgs. 22-23). For example, despite some improvement, rates in Texas and Louisiana continue to be considerably higher than rates in New England or the Mid-Atlantic States. CMS conducts more frequent calls with regional office and State agency staff in States with persistently high antipsychotic use rates in order to review State agency performance and ensure consistent regulatory standards.

Another purpose of the calls with survey agencies is to maintain an open dialogue with surveyors about any issues or challenges in determining compliance with dementia care practices and unnecessary medications and to develop targeted improvement plans. CMS presents data to each State about the number of deficiency citations at F329 and the scope and severity of those citations (see Tables 1-4, pgs. 27-29), as well as the percentage of surveyors who viewed the three mandatory training videos. The rate of antipsychotic use in each State is compared with regional and national averages, and the group discusses promising practices in their region, as well as focusing on facilities with persistently high rates of use and non-compliance. CMS regularly reminds survey agencies that data from QI reports with prevalence rates for antipsychotic use must be obtained and shared with all surveyors on the team prior to the entrance conference. CMS further made it a standard of practice that the survey team leader asks facility leadership to provide an overview of dementia care to the survey team during the entrance conference.

CMS worked with survey agencies to emphasize interviews and observation during the survey of dementia care, as well as the record review. In particular, CMS encouraged interviews with frontline caregivers (e.g., CNAs, recreational therapists and others) as well as family members. In order to reduce reliance on medications in people exhibiting behavioral manifestations of dementia, staff must have detailed information about a resident's prior routines and preferences, to the extent possible. Simple approaches to daily care that include the resident's prior routines may make the difference between a resident who is able to work with staff to receive care, versus a resident who is documented as being, "resistive to care." Interviews with staff and

observations of the interactions with residents may also reveal issues with adequacy of staffing, training or supplies. CMS discusses these topics on regular survey agency calls.

In terms of reducing unnecessary antipsychotic medication use, surveyors were encouraged to speak with physicians, nurse practitioners, and other prescribers about how decisions are made to use or not to use antipsychotic medications in residents with dementia. Surveyors were also encouraged to identify whether or not there is effective communication among the nursing staff, medical team, consultant pharmacist and family around prescribing decisions.

The revised guidance at F309 and F329 encourages surveyors to consider communication among disciplines, across shifts and between weekday and weekend staff, as well as between staff and prescribers, behavioral health teams and family members. This is an essential component of dementia care; failure of the team to communicate effectively must be considered and appropriately cited as deficient practice.

Regional offices are working with State agencies on Federal surveys, to ensure that State surveyors are knowledgeable about current dementia care practices and are able to relate current dementia care standards to other associated issues. For example, reduction in bed and chair alarms that improves the noise level and promotes a less chaotic environment was associated with a reduction in dementia-related behaviors. In summary, CMS addressed enforcement by revising surveyor guidance, developing mandatory surveyor trainings and establishing regular, ongoing communication with survey agency leaders to facilitate better detection of deficient practices and promote consistent enforcement across States and Regions.

## Summary and Next Steps

### CMS Will Set New Goals in 2014

Now that the 15% goal has been achieved, CMS will set a new target for long-stay prevalence of antipsychotic medication use. Of note, some States already set their own State specific goals; for example, California targeted a 30% reduction in their prevalence of antipsychotic use. CMS is also considering a target for reduction in the short-stay incidence of antipsychotic medication use.

CMS is actively engaged in seeking input from measurement experts and others with respect to additional measures of person-centered care and dementia care practices in an effort to consider balancing measures, beyond current metrics that quantify antipsychotic medication use. CMS will evaluate and test new measures of dementia care over the next 18 months.

### **CMS Will Revise Guidance as Needed, Based on Surveyor Feedback and Enforcement Trends**

CMS received recommendations to consider separating out Dementia Care Practices from the rest of the surveyor guidance at F309, since that tag includes several quality of care areas such as pain, hospice and others. CMS also received recommendations to separate out antipsychotic use from other unnecessary drug use currently addressed in F329. CMS is working with national measurement experts to evaluate the potential consequences of making those changes.

CMS will continue data analysis of State to State and regional variation in enforcement activity, particularly around scope and severity.

### **CMS will Monitor Outcomes from Direct Outreach, Enforcement Activity and Other National Partnership Efforts**

Subsequent reports will include results on sustainability of antipsychotic medication reduction in facilities that received specific outreach by members of the National Partnership. CMS will also examine outcomes from intensive work with State survey agencies, regional offices and increased enforcement, as well as outcomes from State-based VBP programs that provide incentives for facilities that can demonstrate improved outcomes related to dementia care. Finally, CMS will continue to monitor potential consequences, such as prescribing shifts from antipsychotic medications to anxiolytics or sedative/hypnotics, as well as changes in functional or cognitive status reflected in the MDS 3.0 data that may result from a shift to more non-pharmacological approaches to dementia care.

### **CMS Will Continue to Facilitate Patient Outcome and Health Systems Research**

CMS plans to follow up on preliminary studies of surveyor attitudes about how the survey process and enforcement may be enhanced and streamlined. CMS and its partners will continue to promote research on improving systems of care in nursing homes, use of individualized, person-centered approaches to care of people with dementia, innovative programs such as telepsychiatry for rural nursing homes, and the effectiveness of this and other national initiatives to reduce unnecessary antipsychotic medication use in nursing homes.

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The National Partnership to Improve Dementia Care is a public-private partnership that encourages grassroots outreach, collaboration and commitment by individuals and organizations in local communities, States and Regions. Furthermore, it engages State and Federal policy-makers, Medicaid, Medicare and other government agencies in working together on critical policy issues. These combined efforts focus on ensuring high quality dementia care in nursing homes, as well as supporting direct care workers and facilities that are striving to improve, and holding facilities accountable if they are not in compliance with State and Federal regulations. Quality improvement principles such as a broad design and scope (everyone is invited to participate); identification of key leaders in each coalition; enhanced public reporting and use of

data; small tests of change to detect and remediate harm; and systematic analysis and systemic action were critical to the early success of the initiative.

Clearly, much more remains to be done to focus nursing homes on person-centered care principles, individualized approaches and a systems-based framework for quality improvement. Many nursing homes across the country demonstrated that these changes may be achievable without a substantial investment in additional resources. CMS and its partners are committed to finding new ways to implement practices that enhance quality of life for people with dementia, protect them from substandard care and promote goal-directed, person-centered care for every resident.

## APPENDIX A: STATE COALITION LEADS

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STATE	NAME
AK	Dennis Murray Sara Bloom
AL	Liz Prosch
AR	Kim Tackett
AZ	Joe Bestic Mary Wiley
CA	Darren Trisel Judy Citko Michael Connors Anthony Chicotel
CO	Penny Cook Amelia Schafer Jane Garramone
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## APPENDIX A: STATE COALITION LEADS

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LA	Barbara Anthony
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MD	Susan Levy, MD
ME	Nina Worsley Brenda Gallant
MI	Audrey Stob May Leonard Yvette McKenzie
MN	Kristi Wergin
MO	Sandy Dailey Deborah Finley
MS	Vanessa Phipps Henderson Wanda Kennedy Brenda Townsend
MT	Clara Rauch-Davis
NC	Cindy DePorter
ND	Michelle Lauckner
NE	Julie Kaminski
NH	Robert Aurilio Angela McCann
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NM	Linda Sechovec

## APPENDIX A: STATE COALITION LEADS

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OK	Mary Fleming Paula Terrel Dorya Huser
OR	Jan Karlen
PA	Dr. David Nace
RI	Nelia Odom
SC	Kim Wilkerson
SD	Lorie Hintz
TN	Beth Hercher Leslie Hays
TX	Susan Purcell
UT	Michelle Carlson
VA	Dr. Mary Evans Dr. Jonathan Evans
VT	Laura Pelosi
WA	Selena Bolotin Sharon Eloranta Traci Treasure
WI	Mary Funseth
WV	Beckey Cochran Pamela Meador Sherry Foltz

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## APPENDIX A: STATE COALITION LEADS

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STATE	NAME
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**Partnership to Improve Dementia Care  
in Nursing Homes  
Federal & State Contacts**

Organization	Contact
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AHRQ	Supriya Janakiraman
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Alzheimer's Association (Missouri)	Zoe Dearing
Alzheimer's Association (New York City Chapter)	Ann Wyatt
Alzheimer's Association, Central & Western Virginia Chapter	Ellen Phipps
Alzheimer's Association of Southeastern Wisconsin	Tom Hlavacek
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Department of Veterans Affairs	Susan Raffa
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RO VIII	Karel Hansmann
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**Partnership to Improve Dementia Care  
in Nursing Homes  
Organizational Contacts**

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Alliance for Aging Research	Sue Peschin
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Alzheimer's Foundation of America	Eric Sokol
American Academy of Nurse Practitioners (AANP)	Jan Towers

American Association for Geriatric Psychiatry (AAGP)	Paul Kirwin
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American Assoc. of Nurse Assessment Coordinators (AANAC)	Diane Carter
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American Physical Therapy Association (APTA)	Marc Goldstein
American Society of Consultant Pharmacists (ASCP)	Arnold Clayman
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"Best Friends Approach to Alzheimer's Care"	David Troxel
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Mercer Medical School (Georgia)	Leon Hyer, PhD
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Music & Memory (Non-Pharmacologic Intervention for people with Alzheimer's disease and related dementias)	Dan Cohen
National Alliance of Mental Illness (NAMI)	Susan Medford
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National Association of Directors of Nursing Administration (NADONA)	Sherrie Dornberger
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National Center for Gerontological Social Work Education	Anita Rosen
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National Network of Career Nursing Assistants	Genevieve (Jeni) Gipson
National Pressure Ulcer Advisory Panel	Robin Turner

National Resource Center for Academic Detailing (NaRCAD)	Jerry Avorn, MD
National Transitions of Care Coalition (NTOCC)/CM-Innovators (CMI)	Cheri Lattimer
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Yale University	Ilse Wiechers, Mary Tinetti

## Appendix B: Partnership to Improve Dementia Care in Nursing Homes Selected List of Accomplishments

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Date	Organization	Description of Accomplishment
<b>Press and Scientific Articles</b>		
October 27, 2011	ASCP Newsletter	“CMS Announces Enhanced Survey Emphasis on Antipsychotic Drug Use in Nursing Facilities”
March 28, 2012	Long Term Living Magazine	“CMS nursing home initiative to address behavioral health, use of antipsychotics”
March 28, 2012	Consumer Voice News Release	“Advocates for Nursing Home Residents Applaud Federal Campaign To End the Use of Antipsychotic Drugs as Chemical Restraints”
January and April, 2012	JAMA	2 published articles related to Initiative
April 19, 2012	Cheryl Clark for HealthLeaders Media	“Feds Urge Cuts in Use of Anti-Psychotic Drugs
April 29, 2012	The Boston Globe	“How the nursing home data were analyzed” by Matt Carroll, Globe Staff.
April 29, 2012	The Boston Globe	“A rampant prescription, a hidden peril” by Kay Lazar and Matt Carroll, Globe Staff.
May 29, 2012	MedlinePlus	“C.M.S. Program Targets Antipsychotic Drug use in Nursing Homes”
May 30, 2012	CMS	Press release: CMS Announces Partnership to Improve Dementia Care in Nursing Homes
June 12, 2012	Lexington (KY) Herald Leader	News article published to Kentucky.com announcing Kentucky’s coalition/Implementation call.
June 26, 2012	American Association of Nurse Assessment Coordination (AANAC)	LTC LEADER newsletter article on CMS National Partnership and antipsychotic reduction: “Antipsychotic Medication Use: QIS Forms Can Help, But No Cure-All”
July, 2012	Provider Long Term & Post-Acute Care	“Solving the Mystery: Providers are finding alternatives to antipsychotics by doing some old-fashioned detective work” by Joanne Kaldy
July, 2012	National Academy of Sciences; IOM Report Draft	“The Mental Health and Substance Use Workforce for Older Adults” Article
July, 2012	AHCA	“CMS Initiative Would Limit Antipsychotics Use”
July 3, 2012	Gary Rotstein for the Pittsburgh Post-Gazette	“Agencies demand curbs on drugs for dementia Difficult patients need new approach”
July 13-19,	Pittsburgh	“Concerns Raised Over Antipsychotic Drug Use”

2012	Business Times	
July, 2012	Providence Journal	New England Blog “Dementia’s Drug Problem” by Cheryl Phillips
September, 2012	The Advocate Baton Rouge, LA	“Targeting Antipsychotics: Program aims to reduce drugs in dementia patients”
September 5, 2012	Des Moines Register - Letter to the Editor	State Leaders Must Appreciate Need to Protect Vulnerable Elderly
October 1, 2012	Letter to Jean Moody-Williams from Chief Ex Officer of TN QIO (Qsource)	Sharing success of the TN State Coalition which is devoted to the National Partnership
October 2, 2012	Senator Richard Blumenthal	“Blumenthal Urges Action to Stop ‘Chemical Restraint’ of Dementia Patients”
April 15, 2013	Wall Street Journal	Interview regarding work under the National Partnership
May 24, 2013	CMS	Release of Revised Guidance and 3 <sup>rd</sup> Mandatory Surveyor Training Video
August 27, 2013	CMS	CMS Press Release – New Data Show Antipsychotic Drug Use is Down in Nursing Homes Nationwide
<b>Recognition by Organizations</b>		
	Pioneer Network	“Integrating the MDS 3.0 Into Daily Practice Webinar Series 3: Individualizing Care: A Performance Improvement Approach to Reducing Anti-Psychotic Medications” launched by Pioneer Network for their National Learning Collaborative Advisory Board Members and Coalition Colleagues
June 29 <sup>th</sup> , 2012	CCAL-Advancing Person-Centered Living	Meeting in Washington, D.C about the Dementia Initiative that will develop consensus recommendations for non-pharmacologic practices that caregivers can use to address behavioral challenges experienced by people who are living with dementia
	Pioneer Network	Promotion of Initiative to Members via E-News
June, 2012	ASCP	Web article announcement: “CMS announces enhanced survey emphasis on antipsychotic drug use in nursing facilities”
July, 2012	New Hampshire LANE	New Hampshire LANE E-Newsletter CMS Partnership recognition
July, 2012	ASCP	Bulletin Announcement “CMS Begins Outreach for Antipsychotics Reduction Program”
July 12, 2012	AMDA	Recognition in their Weekly Bulletin
September 6, 2012	National Consumer Voice	Webinar: Misuse of Antipsychotic Medications in Long-Term Care
<b>Presentations</b>		
December 12, 2011	National Stakeholders	Presentation on the development process of CMS plans for the Partnership with successful collaboration

<b>December 20, 2011</b>	Advancing Excellence, Leading Age, and AHCA	Presentation on the development process of CMS plans for the Partnership with successful collaboration
<b>January 10, 2012</b>	Advancing Excellence Board	Presentation at the Advancing Excellence Board Meeting
<b>February 8, 2012</b>	Massachusetts Senior Care Foundation	Presentation to the Massachusetts Senior Care Foundation
<b>March 2, 2012</b>	American Geriatric Society (AGS)	Presentation to the American Geriatric Society
<b>March 5, 2012</b>	Stakeholder Partners	Second Stakeholder Partner Presentation on the Partnership; Updates provided
<b>March 29, 2012</b>	Kick-off Video	Rollout of Initiative Kick-Off via Video Streaming
<b>April 9, 2012</b>	Part D Group Presentation (AMA, ACP, AAFP)	Convened by Medicare
<b>April, 2012</b>	National State Medicaid Associations	Presentation to National State Medicaid Associations
<b>April 10-11, 2012</b>	Technical Expert Panel	Initiative Technical Expert Panel (TEP) was held
<b>April 12, 2012</b>	CMS Skilled Nursing Facility (SNF)/Long Term Care (LTC) Open Door Forum	Presentation at SNF Open Door Forum
<b>April 24, 2012</b>	Survey and Certification Group	Presentation at the Survey and Certification Group (SCG) Annual Leadership Summit
<b>June 12, 2012</b>	Advancing Excellence and LANE	Presentation with Advancing Excellence and State LANE representatives
<b>June 13, 2012</b>	QIG and QIO	Presentation with QIG and QIO State Agencies
<b>July 2, 2012</b>	U.S. Senate Aging Committee Field Hearing	Convened by Senator Blumenthal
<b>July 17, 2012</b>	Jodie Anthony (CMCS) State Training Coordinator Conference	Updated Medicaid Associations on Initiative efforts
<b>July 17, 2012</b>	Medicare	Presentation at the State Training Coordinator Conference
<b>August 7, 2012</b>	Medicare	Mental Health/Disability Part-D Conference Call
<b>August 23, 2012</b>	CMS Skilled Nursing Facility (SNF)/Long Term Care (LTC) Open Door Forum	Presentation at SNF Open Door Forum
<b>September 12, 2012</b>	Lead (Leaders Engaged on Alzheimer's Disease) Coalition Group	Presentation to the LEAD Coalition Group
<b>September 18, 2012</b>	Technical Expert Panel Follow-Up	Call with Technical Expert Panel attendees/invitees; Updates provided

<b>November 20, 2012</b>	National Stakeholders	Third National Stakeholders call; Update provided
<b>December 4, 2012</b>	State of Connecticut	Presentation on National Partnership
<b>December 4, 2012</b>	State of California	Pre-taped Presentation on National Partnership
<b>December 11-13, 2012</b>	QualityNet Conference	Several presentations at the QIO QualityNet Conference
<b>December 17, 2012</b>	State of Ohio	Presentation on National Partnership
<b>January 31, 2013</b>	National Providers	Presentation on National Partnership through the Medicare Learning Network
<b>February 26, 2013</b>	National Stakeholders	Fourth National Stakeholders call; Update provided
<b>March 19, 2013</b>	HRSA	Presentation on National Partnership and QAPI
<b>April 10, 2013</b>	Survey & Certification Group	Presentation at the Survey and Certification Group (SCG) Annual Leadership Summit
<b>April 10, 2013</b>	CMS	Health Care Communities Portal Site went live
<b>May 8, 2013</b>	State of Missouri	Presentation to Missouri State Coalition
<b>May 16, 2013</b>	CMS	Presentation to Advancing Excellence
<b>May 16, 2013</b>	State of New Mexico	Presentation to New Mexico State Coalition
<b>June 4, 2013</b>	National Stakeholders	Fifth National Stakeholders call; Update provided
<b>July 8, 2013</b>	State of Massachusetts; National Stakeholders	Presentation to Massachusetts State Coalition & ASCP
<b>July 10, 2013</b>	National Providers	Presentation on National Partnership through the Medicare Learning Network
<b>September 9, 2013</b>	National Stakeholders	Presentation at NGNA
<b>September 10, 2013</b>	National Stakeholders	Sixth National Stakeholders call; Update provided
<b>September 27, 2013</b>	State of Kansas	Presentation to Kansas State Coalition
<b>October 10, 2013</b>	State of Michigan	Presentation to nursing homes and Partner Stakeholders
<b>October 31, 2013</b>	CMS	Commonwealth Fund - Presentation on Antipsychotics and Dementia (Toby Edelman & Dean Lerner)
<b>November 12, 2013</b>	CMS	Presentation to State Training Coordinators
<b>November 25, 2013</b>	National Providers	Presentation on National Partnership through the Medicare Learning Network
<b>December 12, 2013</b>	CMS Skilled Nursing Facility (SNF)/Long Term Care (LTC) Open Door Forum	Presentation on SNF Open Door Forum
<b>December 13, 2013</b>	State of Kansas	Presentation to Kansas State Coalition

<b>February 5, 2014</b>	CMS	Presentation on Hospital Open Door Forum
<b>January 29, 2014</b>	CMS	Seventh National Stakeholders call; Update provided
<b>January 31, 2014</b>	State of Pennsylvania	Presentation to Pennsylvania State Coalition
<b>February 26, 2014</b>	National Providers	Presentation on National Partnership through the Medicare Learning Network
<b>March 6, 2014</b>	Regional Office VI; State of Texas	Presentation to Texas Nursing Home Associations
<b>Outreach</b>		
<b>Monthly</b>	Advocacy Community	Monthly meetings held to discuss implementation of Partnership
<b>Monthly</b>	Stakeholder Groups	Coordination calls with Advancing Excellence & QIG (Quality Improvement Group)
<b>Monthly</b>	Leading Age, Advancing Excellence, NHQCC, QAPI	Monthly meetings held to discuss implementation of Partnership and alignment strategies for complementary initiatives
<b>Ongoing</b>	CMS	196+ answered inquiries on the email account created for Partnership: dnh_behavioralhealth@cms.hhs.gov
<b>Ongoing</b>	Consumer Groups	Meetings held on an ad-hoc basis to discuss implementation of Partnership and development of consumer tools
<b>Ongoing</b>	Prescriber Groups	Meetings held on an ad-hoc basis to discuss implementation of Partnership
<b>April 2, 2012</b>	Ruta Kadonoff (AHCA)	E-mail outreach to state executives about Partnership
<b>June-Sept 2012</b>	CMS	50 State Implementation Calls completed
<b>July 2, 2012</b>	Cathy Lieblich (Pioneer Network)	E-mail outreach to members of Pioneer Network to join state coalitions
<b>July 3, 2012</b>	Louisiana Nursing Home Association, Laurie Hinrichs	Wrote to member Nursing Facility Administrators (in 277 member long term care facilities) a letter drafted from the AMDA letter; She asked the information be delivered to medical directors and to emphasize the need to re-evaluate the usage of anti-psychotic medication as well as dementia care in elderly residents.
<b>August 13, 2012</b>	National Culture Change Subject Matter Experts	Discussion to strategize most effective approach to the incorporation of culture change practices into the implementation of the Partnership
<b>November 4, 2012</b>	National Culture Change Subject Matter Experts	Follow-Up discussion to strategize most effective approach to the incorporation of culture change practices into the implementation of the Partnership
<b>November 9, 2012</b>	AIMM (Alliance for Integrated Medication Management)	Discussion to educate and collaborate on the Partnership

<b>Nov 2012-Jan 2013</b>	CMS	Regional Follow-Up Calls with State Coalitions devoted to the Partnership
<b>December 5, 2012</b>	Medicare Learning Network	Discussion and ongoing collaboration to utilize the services of the Medicare Learning Network for outreach on a national level to FFS providers
<b>February-June 2013</b>	CMS	State Coalition Lead(s) Outreach Calls
<b>March 15, 2013</b>	IL Dept of Human Services	Update on Illinois Antipsychotic Project
<b>March 27, 2013</b>	CMS	Quarterly meetings with AGS & AAGP
<b>March-May 2013</b>	CMS	Regional Follow-Up Calls with State Coalitions
<b>June 21, 2013</b>	CMS	Nevada State Coalition Lead outreach call
<b>June 24, 2013</b>	CMS	Call with APNA
<b>June 25, 2013</b>	CMS	Call with Core Geriatric Nurse Coalition
<b>June 28, 2013</b>	CMS	Call with NICHE
<b>June 2013-April 2014</b>	CMS	Outreach Calls to Providers; 19 completed to date; Work is ongoing
<b>July 2, 2013</b>	CMS	Call with AHRQ
<b>August-Sept 2013</b>	CMS	Regional Follow-Up Calls with State Coalitions
<b>September 4, 2013</b>	IL Dept of Human Services	Update call on Illinois Antipsychotic Project
<b>September 6, 2013; November 12, 2013</b>	CMS	Utah State Coalition Lead outreach call
<b>November 7, 2013</b>	CMS	Louisiana State Coalition Lead outreach call
<b>November 20, 2013</b>	CMS	Nebraska & Mississippi State Coalition Lead outreach calls
<b>November 21, 2013</b>	CMS	Arkansas & Wyoming State Coalition Lead outreach calls
<b>December 20, 2013</b>	CMS	Call with SHM
<b>January 9, 2014</b>	CMS	Call with GAPNA
<b>January 13, 2014</b>	CMS	Texas State Coalition Lead outreach call

<b>January 14, 2014</b>	CMS	California Coalition Lead outreach call
<b>February 5, 2014</b>	CMS	Call with APA
<b>February- March, 2014</b>	CMS	Regional Calls with 10 CMS Regional Offices and State Agencies to discuss Enforcement Issues
<b>February 24, 2014</b>	CMS	Call with NAAP



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June 18, 2012

Dear Medical Director,

Over the past few months, AMDA-Dedicated to Long Term Care Medicine has partnered with the Centers for Medicare & Medicaid Services (CMS), as well as several other organizations, in an effort to improve care provided to nursing home residents with dementia under a new, joint behavioral health initiative.

Dementia can significantly impair a resident's ability to effectively communicate his/her needs and concerns. Communication attempts may appear as behaviors that are disruptive or distressing. It is therefore essential to gain an understanding of what is driving these behaviors prior to initiating an intervention or treatment. Sometimes these behaviors may result from an undiagnosed medical condition, an adverse reaction to medication, unmet physical need, or mental illness.

In April 2011 the Department of Health and Human Services Office of Inspector General (OIG) released the report, *Medicare Atypical Antipsychotic Drug Claims for Elderly Nursing Home Residents* (<http://oig.hhs.gov/oei/reports/oei-07-08-00150.pdf>). The report found that in some circumstances antipsychotic medications are being prescribed in an attempt to manage the behaviors of patients with dementia and psychological symptoms, but who did not have an approved indication for their use. While off label prescribing in this context does not always constitute inappropriate prescribing, use of antipsychotic drugs do have significant health risks in this population. This report, and other recent reports, has led to heightened regulatory, legislative, and consumer awareness of the potential dangers these medications may cause for individuals with dementia. Such efforts also complement the recently released, "*Draft Framework for the National Plan to Address Alzheimer's Disease*" by the U.S. Department of Health and Human Services.

**We are asking you, as the medical director of your facility, to join with AMDA and CMS, in the nationwide effort to reduce the unnecessary use of antipsychotic agents by refocusing the interdisciplinary team on a better understanding of the root cause of dementia related behaviors.**

**In this regard, we encourage you to share and discuss the following information with your facility.**

## Medical Director's Role as Clinical Leader in Dementia Care

The medical director leads the team that provides the clinical care to the residents in the facility. In that role, medical directors should help to implement policies and procedures that promote a process of person-centered care, learning "the story" behind each resident, evaluating the behavior changes and excluding potential medical causes of behavioral symptoms. If policies are already in place, the medical director should help to educate the team in existing policies and procedures and ensure that those policies have been implemented. Nursing home policies should direct the staff to identify resident-specific needs, optimize choices, and promote consistent assignment so that staff knows residents well enough to meet their specific care needs. Education should foster the staff's understanding of dementia-related behavior as a form of communication.

Policies should also promote staff's ability to identify relevant risks to any medication, provide parameters for monitoring medications, and institute a process for staff and prescriber reassessment of the resident's response to treatment over time. While there is an established, evidence-based role for antipsychotic medications in managing psychoses, such as schizophrenia and bipolar mania, we are concerned about potential unnecessary use of these medications in persons with behavioral and psychological symptoms related to dementia (BPSD). Medical directors are encouraged to educate facility staff, residents and families about appropriate use of antipsychotic medications, and to begin an ongoing dialogue and collaboration that focuses on non-pharmacologic interventions and person-centered dementia care for BPSD. Educational efforts should also address proper monitoring and the tapering of antipsychotic drugs when used.

As part of the facility's Quality Assessment and Assurance Committee, the medical director along with the administrator, consultant pharmacist and director of nursing should assist the facility with a review of the processes of care for those residents with BPSD on antipsychotic medications. Questions medical directors often ask during the review include the following:

- How many residents in the facility with BPSD receive antipsychotic medications and how is the use monitored?
- What is the process in the facility to initiate the use of these medications?
- What is the process for gradual dose reduction and discontinuation of these medications?
- How is the resident/family/or legal representative informed of the risks and benefits of the use of these medications? How are these discussions documented?

## Use of An Interdisciplinary Team

One effective practice for monitoring the use of antipsychotic medications in a facility used by several of our AMDA members is to have the medical director work closely with an interdisciplinary team composed of nursing, social services, therapeutic recreation specialist and a pharmacist. This team meets regularly to review psychotropic drug use. Individual residents are discussed by the team during their quarterly assessments, or with initiation of psychotropic medications, or when there has been a change in the condition of a resident taking a psychotropic medication. During the meeting, the care plans and medical records are reviewed and resident's functional status, medications, presence of medication side effects and presence or absence of achieved goals for medication use are discussed. This practice emphasizes person-centered care. Recommendations from the interdisciplinary team are then made to or with the resident's attending physician. The team tracks the recommendations for acceptance by the primary care providers and effectiveness in the quality of care for the

resident. This information is further reviewed by the facility Quality Assessment and Assurance Committee for effectiveness in addressing the needs of the residents in the facility.

AMDA has developed comprehensive resources to assist medical directors with these issues. These include talking points, a medication management manual, clinical practice guidelines, a series of webinars, and a handbook for nursing home staff. A complete listing of AMDA resources is attached to this letter.

AMDA looks forward to working with you to improve long term care by standardizing our practices, educating the interdisciplinary care team, further developing strong relationships with residents and their advocates, and supporting caregivers in long term care. Increased prescriber training will help reduce unnecessary antipsychotic drug prescribing. AMDA looks forward to an ongoing collaboration with its medical directors.

Sincerely,

Matthew S. Wayne, MD, CMD  
President AMDA

#### **AMDA Resources**

- In 2011, AMDA released a series of talking points entitled "Appropriate Prescribing of Antipsychotics" to help minimize the *potential for inappropriate prescribing of psychoactive medications* ([http://www.amda.com/advocacy/AMDA\\_Antipsychotics\\_Tlkg\\_Pts.pdf](http://www.amda.com/advocacy/AMDA_Antipsychotics_Tlkg_Pts.pdf)).
- AMDA has several tools for clinical use in the nursing home including:
  - Clinical Practice Guidelines: To establish best practices for medical staff, AMDA has developed clinical practice guidelines on dementia, delirium, and acute problematic behavior for use as evidence-based tools to guide care.
    - <http://www.amda.com/tools/guidelines.cfm>
  - *Mental Health Documentation in the Nursing Home* and *Practical Psychiatry in the Long Term Care Home: A Handbook for Staff*, which is aimed at educating nursing and other staff.
    - <http://www.amda.com/tools/mentalhealth.cfm>
  - *Multidisciplinary Medication Management Manual*, provides practitioners in long term care with information and tools to help them improve patient care, enhance medication management, and reduce medication errors. This manual includes a chapter on appropriate prescribing of psychoactive agents in the long term care setting, which is designed to help guide physicians regarding such issues as the clinical and regulatory documentation necessary when residents are prescribed psychoactive medications.
    - <http://www.amda.com/resources/print.cfm#MED>

- AMDA has hosted a series of educational Webinars on the issue including:
  - *Medication Management: the Doc, F329, and the OIG*. The learning objectives for this webinar included: delineating medication management as it is regulated in nursing homes; discussing the May 2011 report by the OIG concerning psychotropic drug use in nursing homes; and discussing roles of the medical director and physicians practicing in long term care concerning optimizing medication management for nursing home resident.
    - <http://www.amda.com/cmefirect/webinars/web1106E.cfm>
  - AMDA's eUniversity is hosting a webinar on June 28th, titled *Medication Management: Antipsychotic Drug Use Reduction 2012*. To learn more and register, visit, <http://www.amda.com/cmefirect/webinars/web1206E.cfm>.
  - *Use of Psychoactive Medications with Special Emphasis on Antipsychotics in the Long-Term Care Setting*. The learning objectives for this webinar included: recognizing how to analyze and evaluate problematic behavior vs. behavioral symptoms related to dementia; discussing approaches to changing or removing triggers for problematic behavior with non-pharmacological approaches; and describing the appropriate use of psychoactive agents in the long-term care setting.
    - <http://www.prolibraries.com/amda/?select=session&sessionID=773>
  - *The True Meaning of Non-Pharmacologic Management of Behavioral Symptoms in Older Adults with Cognitive Impairment* emphasized the use of non-pharmacologic interventions as the first-line approach to managing disruptive and/or potentially dangerous behavioral symptoms in persons with dementia. The webinar provided a comprehensive, multi-disciplinary approach to these challenging clinical situations and also provided participants with knowledge enabling them to effectively design and implement non-pharmacologic interventions in their facilities.
    - [http://amda.networkats.com/members\\_online/members/viewitem.asp?item=WEB1112E&catalog=SELF&pn=1&af=AMDA](http://amda.networkats.com/members_online/members/viewitem.asp?item=WEB1112E&catalog=SELF&pn=1&af=AMDA)
- More resources on this topic are also located here: <http://www.amda.com/advocacy/brucbs.cfm>

[Insert Name and Address of Facility]

The Centers for Medicare and Medicaid Services (CMS) has identified reducing the off-label use of antipsychotics in nursing facilities as a top priority in 2012. Below you will find your 2011 4<sup>th</sup> quarter data calculated by CMS. This is the time period that will be used as the baseline in assessing achievement of the CMS and AHCA national goal of a 15% reduction in off label use of these medications.

Your Rate <sup>1</sup>	Top Performing Peers <sup>2</sup>	State Average	National Average

<sup>1</sup> Please note: In March 2012, AHCA provided nursing homes above the national average with their 3rd quarter 2011 antipsychotic rate. Subsequently, CMS modified the measure specifications by no longer excluding individuals with a bipolar diagnosis, which may impact the 2011 results sent to some facilities.

<sup>2</sup> This represents the average of the top 25% of facilities showing the lowest antipsychotic medication use in your state.

This measure is based on MDS 3.0 data from the 4<sup>th</sup> quarter of 2011. It is calculated by dividing the number of long-stay residents (in the facility for more than 100 days) with antipsychotic drug use by the total number of long-stay residents. Residents with diagnoses of schizophrenia, Huntington's disease, and Tourette's syndrome are excluded. For more details, view the measurement summary on our website at <http://qualityinitiative.ahcancal.org>. CMS will post this information on Nursing Home Compare in mid-July (approximately 19th). You can also access your data by logging into AHCA's free member resource LTC Trend Tracker. LTC Trend Tracker allows you to compare your facility to a variety of selected peer groups and to see trends in your measures over time. To register for this **free** AHCA member benefit please visit: <http://www.ahcancal.org>.

**What can you do today?** There are several steps you can implement quickly and simply to make progress on this goal:

- There is no role for use of these medications on an as-needed (PRN) basis only since it takes 3-7 days before the medication's antipsychotic effect starts.
- Use of these medications for 3 months or more (particularly if there has been no change in dose or frequency OR those on very low doses) should be assessed for discontinuation or gradual dose reduction. Cumulative benefits begin to be outweighed by cumulative risks as these meds are used for longer periods of time.
- Individuals admitted on these medications without a clear indication or on low dose should be given a trial off of these medications.
- Facilities should implement a review process to ensure that all antipsychotic prescriptions initiated (particularly those during the evening/night shift or on weekends) are critically evaluated soon afterward (e.g. once a week). See below for review questions to ask.

**Four critical review questions to ask:**

When considering use of an antipsychotic drug or reviewing their recent initiation, ask the following questions:

1. What was done to try to figure out why the resident was doing <fill in blank with behavioral response>?
2. What might the resident be trying to communicate to us by doing <fill in blank with behavioral response>?
3. What do we believe the reason was for the resident doing <fill in blank with behavioral response>?  
(Unacceptable answers are "dementia" or "sun-downing")
4. What alternative approaches were tried before requesting these medications?

Encourage staff to look beyond behavior as only a symptom of disease and to explore all possible things the person may be trying to communicate about an unmet physical, emotional, or psychosocial need.

### More Resources

AHCA has resources available to assist you in addressing this issue. Learn how to evaluate problem behaviors in dementia and identify non-pharmacological strategies to treat problem behaviors by viewing the on-demand webinar on Reducing the Off-Label Use of Antipsychotics <http://webinars.ahcancal.org/session.php?id=9002>.

Visit the **Resources** section on our website at <http://qualityinitiative.ahcancal.org> to view all our resources.

Additionally, this year's AHCA/NCAL Convention will host a number of sessions specific to this topic. We invite you to join us in Tampa and attend "Dementia Beyond Drugs: Changing the Culture of Care," to learn about effective ways to empower people living with dementia and create a drug free environment using the experiential model. More details on this and other Convention sessions can be found at: <http://s4.goeshow.com/ahca/annual/2012/index.cfm>.

[Insert Paragraph on state specific resources or meetings on this topic]

### Additional Questions?

Please contact us at [qualityinitiative@ahca.org](mailto:qualityinitiative@ahca.org).

DEPARTMENT OF HEALTH & HUMAN SERVICES  
Centers for Medicare & Medicaid Services  
Dallas Regional Office  
1301 Young Street, Room 827  
Dallas, Texas 75202



**DIVISION OF SURVEY & CERTIFICATION, REGION VI**

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TO: Texas Nursing Home Administrators

FROM: Gerardo Ortiz  
Associate Regional Administrator, Dallas Division of Survey & Certification

RE: National Partnership to Improve Dementia Care in Nursing Homes

In 2012, the Centers for Medicare & Medicaid Services (CMS) announced an important initiative, the National Partnership to Improve Dementia Care in Nursing Homes. Today, I am sending this memorandum to each Texas nursing home to encourage participation in this Partnership. I have included links to relevant websites and information about Partnership involvement in Texas.

Each State has a coalition of groups dedicated to this Partnership. These coalitions provide training, information and support for any nursing home in their State. In Texas, this coalition is led by the Texas Medical Foundation, and the contact is Susan Purcell at [spurcell@tqio.sdps.org](mailto:spurcell@tqio.sdps.org).

This Partnership involves the use of antipsychotic medications in our nation's nursing homes, with the hoped-for outcome of reducing use of these medications unless there is a valid clinical indication. In 2011, before this initiative began, the national rate of use of antipsychotic use was 23.9% across the nation. The most recent report in 2013 shows this rate has reduced to 20.75%, so we believe these efforts have been beneficial. During these same time frames, the rate of antipsychotic use in Texas was 28.9% (in 2011) with a decrease to 26.9% in 2013. Still, even with this 2% decrease, Texas leads the nation in the rate of use of antipsychotic medications for nursing home residents, ranking 51 of 51 states/territories.

Interested? You can find more information about the Partnership at the following website: [http://www.nhqualitycampaign.org/star\\_index.aspx?controls=dementiaCare](http://www.nhqualitycampaign.org/star_index.aspx?controls=dementiaCare). (Alternately, search "advancing excellence, partnership.")

In addition, CMS has funds available for programs and training related to this Partnership. The guidelines for this process can be found in a letter at this link: [http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/SCLetter12\\_13.pdf](http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/SCLetter12_13.pdf). For more information, I encourage you to contact the Texas Department of Aging & Disability Services, your state survey agency.

Enclosed is a poster with more information; please consider posting it within your facility. For additional information, please contact Susana Cruz of CMS Dallas at [susana.cruz@cms.hhs.gov](mailto:susana.cruz@cms.hhs.gov).

Thank you.

# Dementia Care Training Crosswalk

Program or Name and Source	Website	Description of Content	Intended Audience	Length – Time to Review	Format (e.g., web based, DVD, etc)	Cost of Program or Resource	Lead Contact Person, Name and contact information
Hand in Hand CMS	<a href="http://www.cms-handinhandtoolkit.info/">http://www.cms-handinhandtoolkit.info/</a>	CMS, supported by a team of training developers and subject matters experts, created this training to address the need for nurse aides' annual in-service training on caring for residents with dementia and on preventing abuse	Nurse Aides and other nursing home staff	Self-Paced	Set of six DVDs with training manual	\$100 for set of six DVDs and manual, or free to download	Michele Laughman <a href="mailto:dnh_behavioralhealth@cms.hhs.gov">dnh_behavioralhealth@cms.hhs.gov</a>
OASIS	<a href="http://www.maseniorcarefoundation.org">www.maseniorcarefoundation.org</a>	OASIS curriculum, designed to help staff meet the needs of residents with dementia; This unique, resident-centered approach to reducing antipsychotic medications focuses on helping all nursing home staff	Nursing home staff	Self-Paced	Web based curriculum, videos, manual, and webinars	Free to download	Laurie Herndon <a href="mailto:lherndon@maseniorcare.org">lherndon@maseniorcare.org</a>  Susan Wehry <a href="mailto:swehrymd@mac.com">swehrymd@mac.com</a>

# Dementia Care Training Crosswalk

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		develop and refine behavioral strategies that will improve quality of life for residents and job satisfaction for staff members					
DICE Johns Hopkins University	<a href="https://www.coursera.org/#course/dementiacare">https://www.coursera.org/#course/dementiacare</a>	Five-week course foundational knowledge in the care of persons with Alzheimer’s Disease and other neurocognitive disorders	Health professionals and students, family caregivers, friends of patients, and others	5 weeks, 3-5 hours per week	Web based videos and lectures, discussion board and exercises	Free, registration required	Helen Kales <a href="mailto:kales@med.umich.edu">kales@med.umich.edu</a>  Laura Gitlin <a href="mailto:Lgitlin1@jhu.edu">Lgitlin1@jhu.edu</a>
University of Iowa IADAPT	<a href="https://www.healthcare.uiowa.edu/igec/iaadapt/">https://www.healthcare.uiowa.edu/igec/iaadapt/</a>	Information and resources to better understand how to manage problem behaviors and psychosis in people with dementia using evidence-based approaches	Clinicians, providers, and consumers	Self-Paced	Web based video and lectures	Free, registration required	Ryan Carnahan <a href="mailto:Ryan-carnahan@uiowa.edu">Ryan-carnahan@uiowa.edu</a>
National Dementia Initiative	<a href="http://www.ccal.org/national-dementia-initiative/white-paper">http://www.ccal.org/national-dementia-initiative/white-paper</a>	White paper presents a conceptual	Clinicians, providers, and	N/A	Literature	Free	Karen Love <a href="mailto:Karenlove4@verizon.net">Karenlove4@verizon.net</a>

# Dementia Care Training Crosswalk

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White Paper		framework for person-centered dementia care as well as recommendations; First step needed to evolve fragmented and impersonal dementia care systems and practices in this country to person-centered ones	consumers				Jackie Pinkowitz <a href="mailto:jpinkowitz@gmail.com">jpinkowitz@gmail.com</a>
Advancing Excellence  Medication Management Tool	<a href="http://www.nhqualitycampaign.org/star_index.aspx?controls=medicationsidentifybaseline">http://www.nhqualitycampaign.org/star_index.aspx?controls=medicationsidentifybaseline</a>	Excel workbook used to gain a better understanding of the ways antipsychotic prescriptions are used in your nursing home; This tool will help you follow the dose and scheduling of these medications, behavioral and symptom changes, interventions attempted, and	Leadership, consumers, and staff	N/A	Tool	Free	<a href="mailto:help@nhqualitycampaign.org">help@nhqualitycampaign.org</a>

# Dementia Care Training Crosswalk

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		Gradual Dose Reduction attempts; The tool will produce summary statistics that will allow you to track your outcomes and progress over time, and which can be entered into the AE website					
CMS/SCG  Mandatory Surveyor Trainings	<a href="http://surveyortraining.cms.hhs.gov">http://surveyortraining.cms.hhs.gov</a>	Training programs on the care of persons with dementia and unnecessary antipsychotic medication use: 1. Provides survey basics related to care of persons with dementia and unnecessary medications 2. Interactive self-study with video clips that walks through portions of an actual nursing	State and federal, long-term care, surveyors	1 <sup>st</sup> - approx. 35 mins  2 <sup>nd</sup> - self-paced; interactive  3 <sup>rd</sup> - approx. 35 mins	Set of 3 online videos	Free, registration required	Michele Laughman <a href="mailto:dnh_behavioralhealth@cms.hhs.gov">dnh_behavioralhealth@cms.hhs.gov</a>

# Dementia Care Training Crosswalk

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		home survey 3. Video-streaming that discusses how to cite severity					
Cares  HealthCare Interactive & Alzheimer's Association	<a href="http://www.hcinteractive.com/essentialz">http://www.hcinteractive.com/essentialz</a>	Alzheimer's Association® essentiALZ® program combines select HealthCare Interactive CARES® online dementia care training with Alzheimer's Association certification exams	Nursing home staff, assisted livings, hospice, home health organizations, adult day programs, governmental and social service agencies, and police, fire, and other first responders and family members	4, 6 & 10 hour courses	Online training	\$24.95, \$39.95 & \$49.95	<a href="mailto:essentiALZ@alz.org">essentiALZ@alz.org</a>
Promoting Positive Behavioral Health:  A Non-pharmacologic Toolkit for Senior Living	<a href="http://www.nursinghometoolkit.com/">http://www.nursinghometoolkit.com/</a>	Toolkit contains resources to help promote nonpharmacologic behavioral health strategies to address behavioral and psychological symptoms of	Senior living communities staff	N/A	Tool	Free	Ann Kolanowski <a href="mailto:amk20@psu.edu">amk20@psu.edu</a>  Kimberly S. Van Haitisma <a href="mailto:kvanhaitisma@abramsoncenter.org">kvanhaitisma@abramsoncenter.org</a>

# Dementia Care Training Crosswalk

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Communities		dementia (BPSD), behaviors that frequently occur in long-term care residential settings, especially among residents with dementia					
AMDA  Dementia CPG for Prescribers  Dementia CPG for Non-Prescribers	<a href="https://amda-training.com/training/">https://amda-training.com/training/</a>	Courses offer a professional development experience that focuses on the recognition, assessment, treatment and monitoring of dementia in long term care settings	Prescribing & non-prescribing clinicians	5-hours each	Online training	Free, registration required  (Must also complete a post-course, 3-month and 6-month evaluation)	<a href="mailto:admin@amda-training.com">admin@amda-training.com</a>

**\*Note:** This is not an all-inclusive list of existing dementia care training programs. If you are aware of another program and feel it should be added to this list, please contact us via email at [dnh\\_behavioralhealth@cms.hhs.gov](mailto:dnh_behavioralhealth@cms.hhs.gov).



# Get the Facts about Antipsychotic Drugs *and* Dementia Care

*Medications can be an important part of the care provided to nursing home residents. However it is critical to monitor their use carefully. This fact sheet focuses on one type of medication: antipsychotics.*

## What are Antipsychotic Medications?

Antipsychotic medications are potent drugs that may have serious side effects. They are indicated to treat conditions and diagnoses such as schizophrenia. They are not generally used for the treatment of symptoms of dementia.

## Why is this an Important Issue?

In the past, the use of antipsychotics to treat people with Alzheimer's Disease and other dementias was often considered an accepted practice. Now we know that antipsychotic medications that are prescribed inappropriately may be dangerous, especially for the elderly and people with dementia. These medications can have serious, life-threatening side effects such as stroke and falls. They may increase the risk of death for elderly residents. There is now a national campaign to stop their inappropriate use.

## How Does this Relate to Dementia Care?

Some people with dementia may, at times, have behavioral symptoms such as: agitation, physical aggression or vocalizations or psychological symptoms ranging from depression and anxiety to hallucinations, delusions and psychosis. These symptoms may be the result of physical discomfort (such as hunger, a headache or an infection) or emotional upset (resulting from things like loud or confusing noises, being touched in a surprising or uncomfortable way or having a daily routine disrupted). Except when there is an immediate danger to the individual or another resident, the current standard of practice is to provide care that keeps residents comfortable and responds to their needs (and symptoms) without drugs whenever possible.

## When May Antipsychotic Medications be Useful?

Antipsychotic medications and other “psychoactive” medications that may make people drowsy or quiet can be helpful in certain limited circumstances, such as when treating a diagnosed psychotic condition (like schizophrenia) or to temporarily alleviate a situation (such as when someone is dangerous to him or herself or others). When prescribed, it is important that the lowest dose possible is used and that care is taken to assess the individual and factors that may be causing the symptoms. Care should be taken to identify and try non-drug approaches to relieve symptoms and, to the greatest extent possible, to reduce and eliminate the use of drugs. Antipsychotic medications should not be used in the long term to mask symptoms by sedating the person. If medications are used to treat behavioral symptoms of dementia in place of good care, this may be a form of chemical restraint and is prohibited by Federal law.

## Residents' Rights

- **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 a medication.
- **Freedom from Chemical Restraints:** It is against the law to give medications that do not benefit the resident, such as for convenience of staff.

## What is Being Done to Stop Unnecessary Use of Antipsychotic Medications?

**Education:** The government is working with nursing homes, physicians and other caregivers, as well as consumer advocates, to improve dementia care and reduce unnecessary medications.

**Transparency:** [Medicare.gov Nursing Home Compare](https://www.medicare.gov/nhcompare) has information on antipsychotic medication use for each nursing home.

**Enforcement:** Federal and State inspectors hold providers accountable for prescribing antipsychotic medications without a specific, appropriate reason for their use.

## What You Can Do

**Be Informed** about antipsychotic medications and residents' rights. See "Resources" below for help and more information.

**Ask to Speak to the Physician or Practitioner:** A physician must supervise a resident's care. Residents have the right to refuse antipsychotic medications or other treatments.

**Contact a Resident Advocate:** Your local Long Term Care Ombudsman or advocacy organization can help. They can be found through The Consumer Voice ([theconsumervoice.org](https://theconsumervoice.org)).

**File a Complaint** with your State department of health.



## Who Can Speak for a Resident

**Resident with Capacity:** If a resident is able to give (or withhold) consent only he or she has the right to do so.

**Resident without Capacity:** The resident's legally authorized representative may give (or withhold) consent.

**Note:** Consent to use an antipsychotic medication may be withdrawn at any time by the resident or representative.

## Questions to Ask the Nursing Home

What is the reason for this medication?

What are the symptoms that the medication should improve?

Did the team attempt to identify the causes of the person's behavior before using medication to address the symptoms?

Did the team try to use non-medication approaches before trying this medication?

How will this medication be monitored and, if possible, reduced? (In regulations, this is called Gradual Dose Reduction).

**Remember:** All nursing homes are required to have a system in place to care for people with dementia. State and Federal inspectors conduct nursing home surveys to ensure that these regulations are followed. See "What You Can Do" and "Resources" on this page.

## Resources

### [medicare.gov/nhcompare](https://www.medicare.gov/nhcompare)

The Federal website provides information on individual nursing homes nationwide, including their rates of antipsychotic medication use. It also has contact information for State oversight agencies, LTC Ombudsmen and the Federal Nursing Home Complaint Form.

### [nursinghome411.org](https://nursinghome411.org)

Nursing home consumer resource website from the Long Term Care Community Coalition with resources on antipsychotic medications.

### [canhr.org/stop-drugging](https://canhr.org/stop-drugging)

The California Advocates for Nursing Home Reform's Campaign to Stop Chemical Restraints in Nursing Homes has a variety of valuable resources including videos and an excellent guide, *Toxic Medicine*.

### [theconsumervoice.org](https://theconsumervoice.org)

The National Consumer Voice has a dedicated page with antipsychotic medication resources, contact information for Long Term Care Ombudsman and State LTC advocates and many other resources.

# Antipsychotic Alternatives

The following information suggests ideas for reducing antipsychotic drug use. A carefully monitored use of the alternatives with frequent reassessment is suggested. Always start by assessing the resident for pain\*.

## General Principles

- Start with a pain assessment.
- Provide for a sense of security.
- Apply the 5 Magic Tools (Knowing what the resident likes to See, Smell, Touch, Taste, Hear).
- Get to know the resident, including their history and family life, and what they previously enjoyed. Learn the resident's life story. Help the resident create a memory box.
- Play to the resident's strengths.
- Encourage independence.
- Use pets, children and volunteers.
- Involve the family by giving them a task to support the resident.
- Use a validated pain assessment tool to assure non-verbal pain is addressed.\*
- Provide consistent caregivers.
- Screen for depression & possible interventions.
- Reduce noise (paging, alarms, TV's, etc.).
- Be calm and self-assured.
- Attempt to identify triggering events that stimulate behaviors.
- Employ distraction methods based upon their work and career.
- Offer choices.

## What to try when the resident resists care

### Therapeutic Intervention

- Evaluate recent medication changes, especially if the behavior is new.
- Determine if the resident is in pain, and if so, why? Treat the pain.\*
- Evaluate whether the care can be performed at a different time.
- Determine if the resident is trying to communicate a specific need.
- Evaluate the resident's sleep patterns.
- Place the resident in bed when he or she is fatigued.
- Evaluate if there has been a change in the resident's routine.
- Provide a positive distraction, or something the resident enjoys.
- Is the resident hungry? Offer the resident a snack prior to providing care.
- Provide a periodic exercise program throughout the day (e.g. A walk to dine program).
- Encourage wheelchair/chair pushups, or assist the resident to stand periodically.
- Provide activities to assess and provide entertainment.
- Encourage repositioning frequently.

### Environmental & Equipment Intervention

- Use assistive devices (wedge cushion, solid seat for wheelchair, side or trunk bolsters, pommel cushion, Dycem, etc.).
- Evaluate the resident for an appropriate size chair and proper fit.
- Evaluate alternative seating to relieve routine seating pressure/pain.
- Use an overstuffed chair, reclining wheelchair, non-wheeled chairs, or wingback chair.
- Place a call bell in reach of the resident.
- Provide an over-bed table for to allow for diversional activities.
- Place a water pitcher in reach of the resident.
- Place the resident's favorite items in their room to provide them comfort.
- Allow access to personal items that remind the resident of their family, especially photos.
- Encourage routine family visits with pets.
- Provide consistent caregivers.
- Evaluate if the resident's environment can be modified to better meet their needs. (i.e. Determine if the resident's environment can be more personalized.)

\* A pain assessment should include non-verbal signs of pain. If you do not have a pain assessment that includes non-verbal identifiers, go to:

<http://www.dads.state.tx.us/qualitymatters/qcp/pain/painad.pdf>

Continued 

## What to consider when resident is disruptive in group functions

### *Therapeutic Intervention*

- Evaluate new medications, antibiotics especially, and assess pain.
- Remove resident from group, evaluate for group stress
- Determine if resident requires toileting.
- Determine if resident is hungry, and if so, provide them with a small snack. If the resident is thirsty, provide the resident a beverage.
- If this is a new behavior in a group, evaluate what is different this time.
- Assure resident has had a rest period prior to group activity.
- Assure there are no medical complications (low/high blood sugar).
- Assure resident is not in pain.\*
- Return resident to group function, if possible.

### *Environmental & Equipment Intervention*

- Determine whether clothing is appropriate for a particular function.
- Evaluate if the resident has well-fitting shoes, and ensure they do not rub the resident's feet.
- Evaluate ambulation devices (wheelchair, walker) that are in good working condition.
- Ensure there is adequate lighting, especially at night.
- Ensure room/function is not overly crowded.
- Ensure room is not too warm or cold.
- Consider providing snacks and refreshments for all group functions.
- Ensure sound in group functions is loud enough so the resident can hear.
- Provide consistent caregivers.
- Evaluate if this program fits into the resident's area of interest.

## What to consider with a sudden mood change, such as depression

### *Therapeutic Intervention*

- Evaluate any new medications and assess pain\*.
- Evaluate for orthostatic hypotension and change positions slowly.
- Reevaluate physical needs such as toileting, comfort, pain, thirst and timing of needs.
- Rule out medical problem (high/low blood sugar changes).
- Engage resident in conversation about their favorite activity, positive experiences, pets, etc.
- Touch if appropriate while recognizing personal body space.
- Anticipate customary schedules and accommodate personal preferences.
- Evaluate balance for sub-clinical disturbances such as inner ear infections.
- Validate feelings and mobilize the resident. For instance, if the resident states, I want to get up, reply, You want to get up? to confirm you heard them correctly. If so, act on the resident's request.
- Evaluate hearing and vision.
- Discern if talk therapy is possible.
- Assess sleep patterns.

### *Environmental & Equipment Intervention*

- Assess for changes in the resident's environment.
- Assess for changes in the resident's equipment.
- Involve family members to assure them that there have been no changes within the family, without the facility's knowledge.
- Provide routines for consistency.
- Provide consistent caregivers.
- Provide nightlights for security.
- Employ the use of a memory box.
- Employ functional maintenance / 24-hour plan.
- Encourage the resident, if able, to verbalize his or her feelings.
- Eliminate noise and disruption.
- Employ the use of a sensory room or tranquility room.

## Verbally Abusive/Physically Abusive

### Therapeutic Intervention

- Begin with medical evaluation to rule out physical or medication problems.
- Evaluate the resident for acute medical conditions such as urinary tract infections, upper respiratory infections, ear infections or other infections.
- Evaluate the resident for pain, comfort and/or other physical needs such as hunger, thirst, position changes, bowel and bladder urges.
- Attempt to identify triggering events or issues that stimulate the behavior.
- Consider using a behavior tracking form to assist in identification of triggers and trending patterns.
- Consult with the resident's family regarding past coping mechanisms that proved effective during times of increased stress levels.
- Provide companionship.
- Validate feelings such as saying, You sound like you are angry.
- Redirect.
- Employ active listening skills and address potential issues identified.
- Set limits.
- Develop trust by assigning consistent caregivers whenever possible.
- Avoid confrontation. Decrease your voice level.
- Provide a sense of safety by approaching in a calm/quiet demeanor.
- Provide rest periods.
- Provide social services referral if needed.
- Provide a psychologist/psychiatrist referral if needed.
- Provide touch therapy and/or massage therapy on the hands or back.
- Reduce external stimuli (overhead paging, TV, radio noise, etc.).
- Evaluate staffing patterns and trends.
- Evaluate sleep/wake patterns.
- Maintain a regular schedule.
- Limit caffeine.
- Avoid sensory overload.

### Environmental & Equipment Intervention

- Use relaxation techniques (i.e. tapes, videos, music etc.).
- Help the resident create theme/memory/reminiscence boxes/books.
- Help the resident create a magnification box to create awareness of the resident's voice level and provide feedback.
- Use a lava lamp, soothe sounders, and active mobile.
- Play tapes and videos of family and/or familiar relatives or friends.
- Move to a quiet area, possibly a more familiar area, if needed. Decrease external stimuli.
- Use fish tanks.
- Encourage family visits, and visits from favorite pets.
- Identify if another resident is a trigger for this behavior.

## Pacing/ Wandering At Risk for Elopement

### Therapeutic Intervention

- Find ways to meet a resident's needs to be needed, loved and busy while being sensitive to their personal space.
- Provide diverse activities that correspond with past lifestyles/preferences.
- Consider how medications, diagnoses, Activities of Daily Living schedule, weather or how other residents affect wandering.
- Evaluate the need for a Day Treatment Program for targeted residents.
- Help resident create theme/memory/reminiscence boxes.
- Provide companionship.
- Provide opportunities for exercise particularly when waiting.
- Pre-meal activities.
- Singing, rhythmic movements, dancing, etc.
- Identify customary routines and allow for preferences.
- Help the resident create a photo collage or album of memorable events.
- Provide structured, high-energy activities and subsequent relaxation activities.
- Take the resident for a walk.
- Provide distraction and redirection.
- Provide written/verbal reassurance about where he/she is and why.
- Alleviate fears.
- Ask permission before you touch, hug etc.
- Assess/evaluate if there is a pattern in the pacing or wandering.
- Assess for resident's personal agenda and validate behaviors.
- Ask family to record reassuring messages on tape.
- Evaluate for a restorative program.
- Perform a physical workup.

### Environmental & Equipment Intervention

- Remove objects that remind the patient/resident of going home (hats, coats, etc.).
- Individualize the environment. Make the environment like the resident's home. Place objects within the environment that are familiar to the resident.
- Place a large numerical clock at the resident's bedside to provide orientation to time of day as it relates to customary routines.
- Ensure the courtyard is safe for the resident.
- Decrease noise level (especially overhead paging).
- Evaluate floor patterns.
- Evaluate rest areas in halls.
- Evaluate camouflaging of doors.
- Evaluate visual cues to identify safe areas.
- Play a favorite movie or video.
- Put unbreakable or plastic mirrors at exits.
- Place Stop and Go signs.
- Evaluate the WanderGuard system.
- Use relaxation tapes.
- Evaluate and use, as necessary, visual barriers and murals.
- Evaluate wandering paths.
- Evaluate room identifiers.

Mrs. Ward-

My sister, Prinnie, was like my second mother. There were twelve children in our family. She was fourteen years older than me, and helped raise me. When I was older, I lived with her and her husband until I got married.

She was married to her best friend for 50 years. They did not have children. They owned a small restaurant. She was a great cook. The business thrived because she had such good relationships with their customers. She was a respectable, considerate, compassionate member of her community.

After her husband died, she kept living in their house, but she would tell me how sad and lonely she was. She kept working part-time as a cashier in another restaurant, to keep busy, but stopped after 3 years. But she was still active in her church – her husband had been a church deacon – and went out with her friends. I saw her almost every day.

Seven years after her husband died, when she was 79, she started forgetting things. She was confused about appointments. Her doctor said she probably had Alzheimer's.

She needed help, and she had help. She had a friend living in her basement apartment who helped with cooking. A caretaker came in part-time to help her bathe, and to help with chores. I did her cleaning and shopping. After a couple of years I moved in with her.

But the next year I got sick, and needed to have surgery. So I wasn't going to be able to take care of her any more. I did a lot of research, and found what I thought was a good nursing home that I could get to easily. I helped her move in but then I wasn't able to visit for a couple of weeks because of the surgery. We had no other family in the area.

When I started visiting again, she seemed to be adjusting all right. She was on the Alzheimer's floor. The only activities were television and church visits on the weekend, but she didn't seem to mind that too much because she had a roommate she liked and could talk to.

But after two months, they moved her off the Alzheimer's floor, because they said she didn't need to be there. She was really upset and confused about the move. She kept asking why they had done this to her, what had she done wrong? She was now in a room with 3 other people she couldn't communicate with. Except for church visits and television, there were no activities, so she would spend the day lying in her bed. I visited almost every day.

After about a month, they moved her back to the Alzheimer's floor, first to one room, then another. She did not get her room back, or her roommate. This made her even more confused. Again, she kept asking what she had done wrong.

The only activity (besides church and television) was when they would move the residents to the dining room to stare out the window. She hated this, and told them she didn't want to go. One CNA told her that if she didn't cooperate about bathing, she would have to go to the dining room, like a kind of punishment. I told the staff a few times that I didn't want her going there to sit, because she didn't want to, but they kept doing it for 5 more months, until I wrote to the administrator

After that she just stayed in her room. She had nothing to do there, either, but that was where she preferred to be. She got more anxious, started sleeping all day, and walking the hallway at night. She fell once, and got pushed by another resident who was also walking at night.

After that the nursing home put her on Risperdol and Ativan. They said this was for her own safety, to keep her from walking at night and falling. Her eyeglasses had gotten lost, and they were supposed to replace them, but never did, so she couldn't see well when she walked. Her clothes kept disappearing. That confused and upset her more, but the social worker got mad at me when I kept asking about them. She said "We have 210 people in this facility; we can't keep up with your sister's clothes."

I didn't know that I had a choice about the drugs. They said they were doing it for her. I trusted them to know what was the right thing to do.

But when she went on the drugs, she wasn't the same person. She remembered me, but she was doped out. She had no energy. And she stopped talking almost

completely. She could say yes, no, fine, but that was it. When her church members visited, she was receptive, but she couldn't talk to them. The little she had left as a person, they took that away. Only one time: an aide said to her "I'm always nice to you" and she said "Yes, you're always nice to me." Then another aide said, "I'm always nice to you, too." And she said: "I don't know about you."

So she was still there, she knew what was going on, she knew bad treatment from good treatment, but she couldn't verbalize things any more. She couldn't say what she wanted, or what she felt.

I tried to talk to the psychiatrist about the drugs, but they never let me do that. I did talk to the nurse about it, but she said it was the best thing for my sister. So she was on the drugs until she died.

Nursing homes were new to my family. We had a lot of sick people in our family, but we were able to keep our family at home. I tried to advocate for my sister, but when you advocated for your loved one, they didn't like that. They wanted you to put her in the facility, and leave them alone. I feel like I did what I could under the circumstances, but it still bothers me.

# Antipsychotic Medicines for People with Dementia



## Guide to Words Used Here

1. dementia (de-MEN-shuh)
2. Alzheimer's (ALTZ-hi-merz)
3. hallucinations (huh-loo-sin-AY-shuns)
4. delusion (duh-LOO-zhun)
5. antipsychotic (an-tee-sy-COT-ick)
6. suspicious (suh-SPI-shus)
7. paranoid (PAIR-uh-noyd)
8. Parkinsonism (PARK-in-sun-izm)



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MAKING HEALTH CARE BETTER

## What is dementia<sup>1</sup>?

Dementia is an illness that makes it harder and harder for a person to remember things and live normally. There are many kinds of dementia.

*Alzheimer's<sup>2</sup> is one kind. People with dementia may also:*

- See or hear things that are not there. These are called hallucinations<sup>3</sup>.
- Believe something that isn't true, even when told otherwise. This is called a delusion<sup>4</sup>.
- Get angry for no clear reason, or for a small problem. These things can be very upsetting for people with dementia and their caregivers. It's important to comfort and support people with dementia and medicines are needed sometimes.

## What are antipsychotic<sup>5</sup> medicines?

Deciding to use an antipsychotic medicine is hard. There are risks. Not everyone is helped. It's important to use them only when needed and only if they help. Other ways to handle dementia should be tried first.

We can't cure dementia. When it's getting worse, you can think about whether using an antipsychotic medicine makes a person's comfort and quality of life better, even if there are risks.

*What antipsychotic medicines can help:*

- Aggressive behavior – hitting, kicking or biting
- Hallucinations – hearing voices or seeing people who aren't there
- Delusions – being suspicious<sup>6</sup> or thinking people are trying to hurt them. This is called being paranoid.<sup>7</sup>
- Other things that can make it very hard to take care of the person

*What antipsychotic medicines do not help:*

- Not being social – when a person doesn't want to be friendly to others
- Not taking care of oneself
- Memory problems
- Not paying attention or caring about what's going on
- Yelling or repeating questions over and over
- Being restless – when it's hard for a person to sit still

## How do I decide if an antipsychotic medicine is right for my loved one?

First, check for other things that might be causing problems. Talk to the doctor or health care team to help figure this out. They might have other ways to help problem behaviors.

## What are the possible side effects of antipsychotic medicines?

They can cause a small increase in some side effects in people with dementia.

**Death:** Research shows that if 100 people with dementia take an antipsychotic medicine, one of them may die sooner because of the medicine. The chance of this is small. There is no way to tell who might die while taking this medicine.

**Stroke:** Research shows that if 100 people take an antipsychotic medicine, one could suffer a stroke because of the medicine. Some kinds of these medicines might have a lower risk for stroke.

**Movement:** In some people, these medicines can affect the part of the brain that controls muscle movement. Most of the time this loss of movement can go away if the medicine is stopped or the dose is lowered. Tell the doctor right away if you see the following movement side effects:

*The person's muscles getting tight, as in Parkinson's disease. This is Parkinsonism.<sup>8</sup> It can cause short steps or a shuffle when walking. The person's hands or arms may shake. This is called a tremor.*

*Sometimes the face can twitch. Rarely, a person can get very stiff and ill, with a very high fever. If this happens, call a doctor or take the person to the emergency room right away!*

**Some things that affect overall health:** Some antipsychotic medicines cause weight gain, very low blood pressure, swelling, changes in thinking, high blood sugar and high cholesterol more than others. It might be OK to try a different kind of medicine.

## How do we know if antipsychotic medicines are helping?

*Get a clear picture of the problems:*

- Before starting the medicine, write down exactly what problems are happening and how often. Do this every week after the medicine starts.
- If the problems are not as bad or don't happen as often, the medicine might be helping.
- If the problem does not get better, talk to the person prescribing the medicine about a lower dose or stopping the medicine.

*Make the Choice:*

Sometimes, no matter what you do, a person with dementia may be aggressive or have hallucinations or delusions. Medicine may be needed if the person is acting dangerous or is very upset and can't be helped in other ways. It may help the person feel better even if there are risks. Think about:

- What would the person have wanted before he/she got dementia?
- What would the person want if he/she knew they were biting, kicking or hitting people?
- If the person is having scary hallucinations or seeing people who aren't there, would he/she want it to stop if a medicine might help?

## CAT Calls



# CHANGING ANTIPSYCHOTIC THINKING

“Help, help, help, help, help.” The repetition of a word or question is likely a cry for comfort and security. It may soothe the person. It may also be a learned behavior, if the person gets attention only after they call out repeatedly. When care providers and elders develop a close, trusting relationship, the constant cry for attention often goes away.

Is it physical? The better you know the elder, the easier it is to identify what they need. Observe the time, day, frequency, and location. Check for hunger, thirst, pain, or the need to toilet (or know you will be there when they need to). Are you they too hot or cold? Are they afraid or worried?

How can we meet their “expressed need” for connection? Consider how loneliness, helplessness, and boredom are cited as the three plagues of the nursing home by Dr. Bill Thomas of the Eden Alternative. Help the person feel connected. Take time to interact at eye level. Hold their hand. Find activities appropriate for them to restore former social roles and battle boredom. Look for ways the person can be helpful, so they feel more connected and “at home.”

### Action steps:

- Investigate carefully to find the cause of distress - emotional and physical.
- Get acquainted. Help the elder feel accepted and connected, not lost or ignored.
- Offer pleasant activity and structure to the day according to their preference.
- Share a snack to provide physical comfort as well as pleasant social contact.
- For repeated questions, post the answer for the person to read for reassurance. Offer notes, photos, or calendars as reminders.

### Don't miss these training opportunities:

- Review how brain changes affect the ability to communicate and that a person is not trying to irritate care partners with their “calls.” Focus on the Module 3 Instructor Guide, pages 20-26 of *Hand in Hand: A Training Series for Nursing Homes*.
- Kathy Laenhue, M.A. offers very creative, easy to follow activity ideas to help people make connections both with others and in their own brains, at <http://www.wisernow.com/>. *Getting to Know the Life Stories of Older Adults/Activities for Building Relationships*, at <http://www.healthpropress.com/>, offers fun ways to learn what really matters to each elder.

### For more information, contact a MO LANE Planning Committee Member:

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- Missouri Pain Initiative • Heartland Kidney Network • Missouri Hospice and Palliative Care Association