

Testimony United State Senate Special Committee on Aging November, 30, 2012

Thank you Chairman Kohl, Ranking-member Corker and Committee Members for the opportunity to speak to you today regarding the important issue of reducing the inappropriate use of antipsychotics in the nursing home and improving the care of individuals with Alzheimer's Disease and related dementia.

My name is Cheryl Phillips. I am a fellowship-trained geriatric physician and have spent over two decades in long term care. I am now the senior vice-president for Advocacy at LeadingAge, formerly known as the American Association of Homes and Services for the Aging

The members of LeadingAge serve as many as two million people every day through mission-driven, not-for-profit organizations dedicated to expanding the world of possibilities for aging. Our 5,700 members, many of whom have served their communities for generations, offer the continuum of aging services: adult day services, home health, community services, senior housing, assisted living residences, continuing care retirement communities and nursing homes. Together, we advance policies, promote practices and conduct research that supports, enables and empowers people to live fully as they age. LeadingAge's commitment is to create the future of aging services through quality people can trust.

According to the Alzheimer's Association in 2011, 13% of Americans 65 years of age and older are diagnosed with dementia, and that number reaches 43% for those 85 and older. It is the 6th leading cause of death in seniors and two-thirds of persons with dementia die in the nursing home. Of those seniors 80 years old and older who have a diagnosis of dementia, 75% will be admitted to a nursing home for long term care. By CMS's own reports between 50 and 75% of long-stay residents in nursing home have some degree of dementia. This is a profound

challenge that faces health care, long term care, and most importantly, the seniors and their families who are in this challenging journey.

But it is important to note that this is neither an issue limited to nursing homes, nor to the United States. Across the globe providers and health policy leaders are grappling with how best to provide care for individuals with dementia, including when and how medications should be used and what are non-medication alternatives. In a recent report to the Minister of the State for the National Health Service in the UK, Dr. Sube Banerjee outlined the challenges of reducing the use of antipsychotics for the management of behaviors related to dementia in the acute hospital, in the community, as well as in the nursing home. He presented eleven recommendations to the NHS, many that closely parallel the approaches proposed below. http://psychrights.org/research/Digest/NLPs/BanerjeeReportOnGeriatricNeurolepticUse.pdf

First of all, it is important to recognize that the use of antipsychotics is related to the much larger challenge of how to provide care for people with dementia. Medications are used often as the first intervention because family members, care givers, nurses and doctors in ALL settings lack information or training regarding alternatives. To merely target this one class of drug as the "problem to be fixed" will have the unintended consequence of increasing the use of other, equally risky medications, such as benzodiazepines, anti-seizure medications and sedativehypnotics, all of which have side effects that include confusion, falls, and risk of death. Furthermore, if the focus is only on the nursing home, we will create barriers to access for care that patients and families desperately need. In some states, such as California where consent rules regarding the use of any psychoactive medications in nursing homes are in place, some nursing homes have declined admissions because of a "history of behavior problems requiring psych meds", creating real challenges for caregivers and often requiring patients to stay for long periods in the acute care hospital. The solution to this challenge is not a short-term fix, but rather a two-fold strategy that involves systemic application of non-pharmacological behavioral interventions as the first line of treatment, with close monitoring for appropriate and limited use of medications when the non-pharmacological approaches have not worked.

We currently have an excellent framework for the definition and avoidance of unnecessary drugs in the nursing home setting in the language of F-329 in the Federal Regulations. The CMS State Operations Manual Appendix PP defines *Unnecessary Drugs* when used;

- i. In excessive dose; or
- ii. For excessive duration; or
- iii. Without adequate monitoring; or
- iv. Without adequate indication for its use; or
- v. In the presence of adverse consequences which indicate the dose should be reduced or discontinued; or any combination of the above.

The guidelines further require that based on a comprehensive assessment of a resident, the facility must ensure that;

- Residents who have not used antipsychotics drugs are not given these drugs unless antipsychotic drug therapy is necessary to treat a specific condition as diagnosed and documented in the clinical record and
- ii. Residents who use antipsychotic drugs receive gradual dose reductions and behavioral interventions, unless clinically contraindicated, in an effort to discontinue these drugs.

In addition to having antipsychotics prescribed in the nursing home, individuals diagnosed with dementia are frequently admitted to the nursing home already on multiple psychoactive medications (antipsychotics, benzodiazepines, antidepressants and others to manage behavior) that were started in the hospital, in assisted living or in the community, and they are merely continued as part of the dementia treatment plan.

There are five simple questions that should be asked when a person is admitted on antipsychotics or when a consideration is made to start them.

- 1. What was/is the *specific* reason for their use? Far too often the answer is reported simply as "aggression" or the normal behaviors related to dementia such as wandering or repetitive vocalizations. If there is no valid indication requiring their use, then dosage reduction and discontinuation should be considered, or the drug should not be started.
- 2. If there was an indication that required the short-term use, does that indication still exist? If not, then dosage reduction and discontinuation should be considered. And if

- the behavior (example: transient agitation related to an event or other health care condition) has resolved then the medication should not be started
- 3. If the person is already on antipsychotics are there any undesirable side effects? If so, dosage reduction and discontinuation should be considered.
- 4. Has the person or their family or caregiver been given information about the use, risks and potential benefits (if any) of the medication being used? If not, then dosage reduction and discontinuation should be considered or the medication not started, except for very short-term use in valid emergencies that pose health or injury risks to the person or others.
- 5. Is there any history that appropriate behavioral therapies have been attempted in lieu of medication management? If not, such should be initiated and there should be a concurrent dosage reduction and discontinuation of the antipsychotic medications and these drugs should not be started, except in short term emergencies without first using these behavioral approaches.

Employing these simple strategies alone will result in significant reductions in the use of antipsychotic medications. But they are not enough to truly change care. The long term answer, much like how physical restraint reduction was implemented, comes from a sustained campaign that teaches caregivers how to provide real person-centered care alternatives. It takes direct care workforce training to apply evidence-based tools and approaches to care for persons with dementia. It takes dissemination of knowledge to nurses and physicians regarding the effectiveness of non-pharmacological interventions and to appreciate the risks of managing behaviors through medications alone, and it requires specific interdisciplinary team monitoring of patients when these medications are used to ensure the indication, dose, duration and response is appropriate for that individual.

This will take a collaborative partnership of ALL stakeholders; CMS, clinical staff and physicians across the health care continuum, pharmacists, direct care workers, and caregivers and families to move toward true "culture change" to improve how we care for people with dementia. It will require accurate aggregate data to measure incidence and prevalence of antipsychotic use with

timely feedback to prescribers and providers of care. It will require large-scale replication research and dissemination of evidence-based behavioral therapies that are effective in the care of people with dementia. It will require enhanced surveyor training, and an investment in meaningful workforce training across ALL settings of care.

We, at LeadingAge are committed to work on this. We have already convened a group of innovative LeadingAge member leaders to share their experiences of how they have improved dementia care in their communities and settings. We have begun an educational campaign to our members regarding avoiding the use of Unnecessary Drugs and Antipsychotics. We look to Advancing Excellence, an established coalition of multiple stakeholders that includes CMS, AHRQ, the Quality Improvement Organizations (QIOs), ASPE, nurses, administrators, consumers, direct care workforce, medical directors and nursing home associations, including LeadingAge, committed to improving the quality of care and life for people living in nursing homes. The work of Advancing Excellence is structured through LANEs (Local Area Networks for Excellence) that draw on regional stakeholders such as Ombudsmen, QIOs, and providers, to implement improvement changes at the local level. It is this level of collaborative work that will be required to both drive true change and sustain quality improvements over time.

In summary, the issue of the inappropriate use of antipsychotics is a symptom of the greater challenge, and if we merely target these drugs we will miss the opportunity to achieve the real improvement we seek. This is also not a "nursing home problem", but rather a systemic health care dilemma. We at LeadingAge recognize that the true measure of quality care for people with dementia is care that is person-centered and based in dignity and compassion for the residents and their families. We can help transform nursing homes into centers of excellence for the care of people with advanced dementia and serve as the learning laboratory for other settings of care.

Respectfully submitted,

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