United States Senate
Special Committee on Aging

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"The Overutilization of Atypical Antipsychotics in Long-term Care Settings"

Good afternoon Chairman Kohl, Ranking Member Corker and distinguished members of the Committee. I am Tom Hlavacek, Executive Director of the Alzheimer's Association of Southeast Wisconsin. Thank you for the opportunity to discuss the very serious problems that overutilization of atypical antipsychotics present for people with Alzheimer's disease, particularly those who reside in long-term care settings.

Today, there are an estimated 5.4 million Americans living with Alzheimer's disease; approximately 30 percent (1.8 million individuals) reside in long-term care or skilled nursing facilities. In 2010, approximately 110,000 Wisconsin residents had Alzheimer's disease. In 2008, of the 74,000 nursing home residents in Wisconsin, almost 70 percent had a cognitive impairment. During the course of their disease, many individuals living with Alzheimer's disease and related dementias will experience behavioral and psychotic symptoms. Depression, hallucinations, delusions, aggression, agitation, wandering, and "sundowning" are hallmark behavioral and psychotic symptoms of dementia (BPSD). Many of these symptoms are the impetus to falls, weight loss, infection, incontinence, and institutionalization for individuals with dementia.

Despite the severity and frequency of these symptoms, there is currently no FDA approved therapy used to treat BPSD. As a result, many types of medications, including atypical antipsychotics, have been used "off-label" in an attempt to mitigate these symptoms. In 2005, the FDA examined this issue and found that the use of atypical antipsychotics in people with dementia over 12 weeks helped to reduce aggression, but was also associated with increased mortality. Subsequently, the FDA issued a black box warning that requires physicians who prescribe antipsychotics to elderly patients with dementia-related psychosis to discuss the risk of increased mortality with their patients, patients' families, and caregivers. Research indicates these drugs also cause additional side effects including stroke, tardive dyskinesia, weight gain, diabetes, sedation, parkinsonism, and worsening of cognition. Thus they must be used with caution and at the lowest effective dose.

Recently, the Office of Inspector General released a report, *Medicare Atypical Antipsychotic Drugs Claims for Elderly Nursing Home Residents*, which found that 88 percent of the reviewed claims for atypical antipsychotic drugs were for elderly nursing home residents with dementia. The report's findings are of concern given the increased mortality risk and the federal regulations and surveyor guidance that specifies each nursing facility resident's drug regimen must be free from unnecessary drugs. The guidance also restricts the use of antipsychotic drugs for nursing facility residents, unless, based on a comprehensive assessment of a resident, the antipsychotics are necessary to treat a specific condition as diagnosed and documented in their clinical record. Instead, the Inspector General's report found that 22 percent of antipsychotic drugs claimed did not comply with CMS standards regarding

unnecessary drugs in nursing homes. The Alzheimer's Association strongly believes that non-pharmacologic approaches should be tried as the first-line alternative to pharmacologic therapy for treatment of BPSD.

Unfortunately, we have seen first-hand what can happen when an individual with dementia is prescribed antipsychotics without proper precautions. At the time of his death, Richard "Stretch" Petersen, a friend of Senator Kohl's, was an 80 year old gentleman with late stage dementia who exhibited challenging behaviors in a long-term care facility. After being at two hospitals in an effort to have his behaviors treated via antipsychotics, he was placed under emergency detention, and was transferred by police in a squad car in handcuffs to the Milwaukee County Behavioral Health Psychiatric Crisis Unit, where his family found him tied in a wheelchair with no jacket or shoes. In spite of his family's efforts to intervene and seek better care, he very quickly developed pneumonia, then was transferred to a hospital, and died. Richard Petersen worked hard all his life, raised his family, and contributed to his community in many ways. He did not deserve to die in the way he did.

Mr. Petersen's death was the latest in a series of incidents in Southeast Wisconsin brought to our attention regarding negative outcomes related to Alzheimer's behaviors. In response to this growing problem, the Alzheimer's Association of Southeast Wisconsin and other concerned stakeholders created the Alzheimer's Challenging Behaviors Task Force. The Task Force's goal is to review and try to resolve problems related to the involuntary commitment and treatment of people with dementia who exhibit challenging behaviors. Through our work, it became clear that everyone works in underfunded and understaffed systems of care, and are often without needed tools and resources.

Our Task Force investigations unfortunately concur with what is contained in the Inspector General's report. Locally, we found these drugs are often poorly prescribed, administered and monitored, leading to negative health outcomes for many persons with dementia. Through our work, we quickly found that negative outcomes were often associated with the relocation of individuals in and out of hospitals, mental health, and long-term care facilities; and a heavy reliance on atypical antipsychotics. In turn, these care transitions for people with dementia often exacerbate challenging behaviors and leads to negative outcomes. The Task Force also found that the use of antipsychotic drugs is often a default to compensate for broader systemic inadequacies in health and long-term care settings.

Rather than focusing on assigning blame, members came together with a willingness to improve care for people living with dementia. The Challenging Behaviors Task Force eventually included 115 members from all sides of the issue including law enforcement, courts, human services, legal advocacy, family caregivers, community and facility long-term care providers, and physicians and nurses from hospital systems. Much of the Task Force's success came from our members' "roll up your sleeves" attitude, which allowed us to publish *Handcuffed*. *Handcuffed* is intended to provide a basic understanding of challenging behaviors among people with Alzheimer's disease and approaches to addressing the problem in facilities and across systems. I have included our report for the record. I am also pleased to report the Task Force is engaged in a second year of activity.

The Task Force is one local example of how, for many years, the Alzheimer's Association has advocated for quality care in long-term care settings across the nation, including the reduction of inappropriate use of antipsychotics to address behavioral problems for individuals with dementia. Recently, the Alzheimer's Association's Board of Directors approved a position statement titled "Challenging Behaviors," which discusses the treatment of BPSD. The

Association maintains the position that non-pharmacologic approaches should be tried as a first-line alternative for the treatment of BPSD. Further, restraint therapies including long-term antipsychotics should be avoided in the treatment of behavioral and psychotic symptoms. Antipsychotic therapy should be utilized only after non-pharmacologic alternatives have been unsuccessful. In addition, antipsychotics must be used carefully and are most effective when combined with non-drug approaches to behavior management. The Association recommends training and education on psychosocial interventions for all professional caregivers. Specifically, the Alzheimer's Association believes *"in making the decision to utilize antipsychotic therapy the following should be considered:*

- *Identify and remove triggers for behavioral and psychotic symptoms of dementia: pain, under/over stimulation, disruption of routine, infection, change in caregiver, etc;*
- *Initiate non-pharmacologic alternatives as first-line therapy for control of behaviors;*
- *Assess severity and consequences of BPSD. Less-severe behaviors with limited consequences of harm to individual or caregiver are appropriate for non-pharmacologic therapy, not antipsychotic therapy. However, more severe or "high risk" behaviors such as frightening hallucinations, delusions or hitting may require addition of antipsychotic trial;*
- *Determine overall risk to self or others of BPSD, and discuss with doctor the risks and benefits with and without antipsychotics. Some behaviors may be so frequent and escalating that they result in harm to the person with dementia and caregiver that will in essence limit the life-expectancy and or quality of life of the person with Alzheimer's disease; and*
- *Accept that this is a short-term intervention that must be regularly re-evaluated with your health care professional for appropriate time of cessation."*

A copy of this position statement has been included for the record.

The Alzheimer's Association strongly believes one mechanism for assessing and responding to behavioral symptoms, as well as improving overall care for residents in long-term care settings, is to raise the level of expertise of nursing facility staff through training and education. To that end, the Alzheimer's Association developed two dementia care training programs specifically for staff in the nursing facility setting: *Foundations of Dementia Care* and the *CARES Program*. Both of these training programs have been identified by the CMS Survey and Certification Group as options for nursing facilities to satisfy the requirements of Section 6121 of the Affordable Care Act, which calls for dementia care training for certified nurse aides (CNAs) working in nursing homes.

The *Foundations of Dementia Care* program provides direct care staff and supervisors with an understanding of dementia and individual resident needs. This training is classroom-based and can be customized to address the needs of each nursing facility, including meeting relevant state regulations. The *CARES Program* is an online training program that provides a variety of modules designed to provide comprehensive dementia education. A new module, *CARES Dementia-Related Behavior*, focuses on non-pharmacologic strategies for reducing or eliminating challenging behaviors. Since the *CARES Program* is an online, modular program, nursing facility staff can be trained as individual schedules permit, rather than in large groups. This allows nursing facilities to mitigate scheduling issues that could otherwise complicate coordinating staff training. Local Alzheimer's Association chapters across the country are excellent resources for these and other training programs to enhance care and support for persons with dementia and caregivers.

Lastly, the Alzheimer's Association *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes* were developed six years ago from the latest evidence in dementia care research and the experience of professional direct care experts. More than twenty organizations supported the recommendations that can improve the care and quality of life for individuals with dementia who reside in these facilities. These recommendations are the basis for every aspect of our Campaign for Quality Residential Care, which establishes standards of dementia care to improve quality of life for people with dementia living in long-term care settings.

Recently, the Alzheimer's Association has participated in discussions with the Centers for Medicare and Medicaid Services (CMS) on the challenges of inappropriate prescribing of antipsychotics in long-term care facilities. These discussions highlighted a variety of reasons that caring for individuals with dementia who experience behavioral and psychotic symptoms is challenging. We look forward to continued dialogue with the Committee, as well as CMS, to promote quality dementia care for all nursing home residents, especially for individuals, exhibiting challenging behaviors.

On behalf of the Alzheimer's Association, I would like to thank the Committee for the opportunity to testify on this important issue. The Alzheimer's Association is committed to ensuring people with dementia have access to high quality care, and as such strongly believes that non-pharmacologic approaches should be tried as the first-line alternative for treatment of behavioral and psychotic symptoms for dementia residents. Chairman Kohl and Ranking Member Corker, we greatly appreciate the opportunity to address this issue and look forward to working with the Committee in the future.