New York State Assembly Committee on Health

Hearing on Use of Antipsychotic Medication in Nursing Homes

Richard N. Gottfried, Chair, Committee on Health

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Testimony presented by

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Thank you , Chairman Gottfried, for the opportunity to discuss the critical issue of the use of antipsychotic drugs in nursing homes. I am Jed Levine, Executive Vice President of the Alzheimer's Association, New York City Chapter. Founded in 1978, the Chapter is one of seven statewide and 83 nationally that deliver services and provide care and support, free of charge. The New York City Chapter serves an estimated 500,000 New Yorkers—those with Alzheimer's and related disorders and their caregivers.

Alzheimer's is a progressive and fatal brain disease, mostly affecting the elderly, which threatens to overwhelm the health care system, if we do not find a way of preventing, slowing it down or curing it one day. Approximately 5 million people in the United States are living with Alzheimer's disease. That number is expected to grow to as many as 13.5 million by mid-century. Every 67 seconds a person in the United States is diagnosed with Alzheimer's disease, and we expect by 2030 there will be 7 million people age 65 and older living with Alzheimer's. The financial ramifications of the disease are daunting and currently cost the country $214 billion annually. We estimate that between 50 – 80% of nursing home residents have dementia, many of those in the advanced stage.

The Alzheimer's Association, New York City Chapter is on the front lines every day providing a wide variety of educational and support programs including over 110 support groups, the MedicAlert + Safe Return Program, a 24-hour Helpline and care consultation services with professional counselors all designed to assist caregivers, family members and persons with dementia develop methods for successfully coping with this progressive and terminal illness. We educate families about long term care, including placing a relative in residential care. We also train home care and other direct care workers to better care for persons with dementia. A major focus for the Chapter is outreach to the Latino, Chinese, African-American, Russian, LGBT, Orthodox Jewish communities and other underserved and immigrant populations.

New York's population is aging rapidly and more attention must be paid to the social and health concerns of seniors, which include Alzheimer's disease and related dementias, associated long-term care requirements, caregiver support, and palliative care.

Alzheimer's is a progressive, terminal disease; the average time between diagnosis and death is 8 to 10 years, but it is extremely variable and can last up to 20 years or more; typically, about 40% of this time is spent in the advanced stages. By age 80, four percent of Americans enter a nursing home. 75% of people with AD at age 80, are cared for in a nursing home

Today, an estimated 380,000 people in New York State living with dementia or Alzheimer's disease are experiencing losses unimaginable to those of us who do not suffer from this illness. Alzheimer's and other dementias are one of the leading causes of dependency and disability in older adults, and as the person with dementia (PWD) progresses through the disease, caregiving responsibilities can overwhelm their family. The advanced stages of Alzheimer's disease leave the patient unable to communicate with words, incontinent, unable to walk, experiencing eating difficulties and requiring 24-hour care, essentially totally dependent on somebody else for all activities of daily living; feeding, grooming, bathing, dressing and toileting. This decline often leads to nursing home placement. In the terminal phase of the illness the individual has no spoken words, difficulty swallowing, confined to bed and experiencing recurring infections.

Caring for a relative with AD is an exhausting and demanding task, one that is often done out of a deep sense of love, duty and filial obligation that often drains the caregiver of their emotional, spiritual, and financial resources. An estimated 90% of persons living with advanced dementia live in nursing homes and residential care facilities; less than 25% percent are referred to hospice or palliative care. Many late-stage dementia patients are given unnecessary and improper medical care, including the use of feeding tubes, intravenous therapy, restraints, and antipsychotics that provide few, if any, long term benefits.[1]

Palliative care, with a major focus on identifying and appropriately treating pain, has the potential to improve care for people with dementia; however, unless there are specific modifications in how palliation is offered to people with dementia, there is a strong possibility that it will be ineffective. Far too often, palliation isn't even considered as an option for people with dementia.

The Alzheimer's Association, New York City Chapter is proud to introduce an innovative approach to palliative care for persons with advanced dementia to New York City, based on the Comfort Matters ™ approach developed at the Beatitudes Campus in Phoenix Arizona. During

[1] Kuhn, Daniel R., Forrest, Jeannine M., Palliative Care for Advanced Dementia: A Pilot Project in 2 Nursing Homes. American Journal of Alzheimer Disease & Other Dementias.

the first year of this 30-month project, a pilot unit in each of the three nursing homes (Cobble Hill Health Center, Isabella Geriatric Center, and Jewish Home LifeCare, Manhattan Campus) has been selected to implement the specific practice changes promoted by Beatitudes. The three hospice programs selected for the project (Visiting Nurse Service, MJHS and Calvary), all have working relationships with some or all of the nursing homes, and are included in this project to ensure their understanding and support for the improvements.

In addition to the practice changes, the project included a robust research component, including extensive evaluation on the three pilot units. This evaluation, which is comprised of five parts, will involve pre-testing before the actual commencing of the project in the fall of 2012, and post-testing, at the completion of the pilot year, in the fall of 2013. The five elements of the evaluation include (1) the Questionnaire of Palliative Care for Advanced Dementia (qPAD (2) the Artifacts of Culture Change for Dementia Care is an assessment process which utilizes structure, process, and outcome measures to determine the extent to which each of the pilot units in the nursing homes provide quality dementia care, , (3) Extrapolating publicly reported MDS 3.0 data from the 3 nursing homes and examining resident outcomes, (4) Pharmacy Cost Study, (5) is another Cost Study which will look at other costs such as use of dietary supplements, use of incontinence supplies, etc.

At the heart of this approach, is the concept that cognitively impaired individuals communicate pain or distress through their behaviors, as they no longer have language to communicate their discomfort. Key to the palliative approach is taking active steps to prevent or avoid unnecessary pain and suffering before they take hold, and to address pain and suffering when it is present. As an individual's dementia advances, his/her actions, rather than words are most likely to communicate distress. These actions often characterized as "resistance to care" i.e. calling out, screaming, yelling, hitting, kicking, pushing away, biting, spitting, are a source of distress for families, and staff alike. Unfortunately, all too often these behavioral expressions are not understood as distress; rather they are often assumed to be the inevitable consequences of the dementia itself. Anti-psychotic and anti-anxiety medications are often inappropriately prescribed. However these medications do nothing to change the situation. Indeed they remove the only means available for the individual to express their discomfort without addressing the root cause; pain, hunger, thirst, fatigue, boredom, or environmental stimulation

Dementia-capable palliative care applies dementia-specific practices and tools to evaluate and to respond appropriately to people with advanced dementia. In particular, this means (1) use of a behavior-based pain assessment tool; (2) use of round-the-clock rather than PRN orders for pain medications; and other measures that address dietary, sleep and environmental concerns, all of which can be a potential source of distress, or comfort.

All of our partner homes have embraced the innovative "Music and Memory" Program, as one of the alternative approaches to care as part of the palliative care program. This approach developed by Dan Cohen, MSW uses personalized playlists of music delivered via iPods to those with dementia, including the advanced stage. The results are often dramatic, inspiring and deeply moving: a true re-awakening of the human spirit, even those who seem totally unresponsive and "gone" come to life, thus proving the ability of those with advanced dementia to respond - the potential for connection and comfort is there, we just need to find the right key. Dan has data that supports the use of individualized music as an attractive and low-cost alternative to anti-psychotics. Indeed, several states have adopted Music and Memory as a means of bringing comfort and pleasure to the residents in their nursing homes, using CMP dollars to pay for the implementation. I would strongly encourage New York State to pursue this as well.

Our hypothesis, based on the successful and impressive results at the Beatitudes Campus, is that the practice of Palliative Care will result in a reduction in the use of anti-psychotics, anxiolytics and sedatives. The Beatitude Campus reports a reduction to between 0% and 5% of their residents receiving anti-psychotics, and they have virtually eliminated the troubling behavioral syndrome known as "sundowning".

The residents served A in Phoenix are no different from the residents we serve in NYC, there is a similar mix of dementia diagnoses, behavioral disturbances, and indeed, they accept residents who are "difficult to serve" and have been rejected from other facilities.

The results of our extensive evaluations are being finalized now, and we will be happy to share those reports with the members of the committee. I am confident that even though there might be variability from site to site, when considered collectively, the results will show a reduction in

the use of anti-psychotics, a judicious increase in the use of pain medications and, also of note, a reduction in pharmacy costs.

The Alzheimer's Association, NYC Chapter also works to educate family members about the benefits of a Palliative Care approach, which will result in the reduction of inappropriate use of anti-psychotics and has developed materials in English, Spanish and Chinese to deliver this message.

We are pleased to report on the use of the Beatitudes Comfort Matters palliative care approach as a proven method of improving care for persons with advanced dementia in nursing homes, which has the added benefit of reducing the inappropriate use of anti-psychotics, and having positive outcomes for staff and family members alike. We are finalizing an implementation guide which will be distributed to all the homes in NYS. Leading Age reports, "According to the latest quarterly update from the Center for Medicare and Medicaid Services (CMS)'s National Partnership to Improve Dementia Care in Nursing Homes, there has been a decrease of **19.4 percent** in the national prevalence of antipsychotic medication use in long-stay nursing home residents since 2011."[2]

We hope to show that models of care that emphasize a palliative care approach, such as Comfort Matters are an integral and critical part of that success. We know that New York State must do even better. Our hope is that this model program will be replicated in every nursing home that seeks to provide excellent care for this most vulnerable population.

We are deeply appreciative of your leadership on this issue. The Alzheimer's Association, NYC Chapter, and the Coalition of NYS Alzheimer's Association Chapters, is available to answer any questions, or provide any additional information as needed.