

Testimony before the Pennsylvania Alzheimer's Disease Planning Committee
August 15, 2013

Good Morning. My name is David Hoffman and I am President of David Hoffman & Associates, a national health care consulting firm that focuses on compliance from a legal and clinical perspective and patient/resident safety. Additionally, I am the President-elect of the Eastern Pennsylvania Geriatrics Society (EPGS). EPGS is the regional affiliate of the American Geriatrics Society dedicated to the goal of advancing high standards of clinical care and quality of life for elderly individuals. The EPGS is a multidisciplinary group of health professionals involved in the care and services for the elderly. I am also a member of the Board of Directors of the Delaware Valley Chapter of the Alzheimer's Association.

Previously, I served as an Assistant United States Attorney for the Eastern District of Pennsylvania where I pioneered the use of the federal False Claims Act as a means to prosecute health care providers who received federal funds and in turn, neglected residents of nursing homes, assisted living facilities, personal care homes and group homes for the mentally disabled. I have seen first-hand unspeakable harm that was perpetrated against some of the frailest and most vulnerable members of our society.

Thank you for the opportunity to speak with you this morning. Any discussion regarding important issues pertaining to individuals with dementia must include the topic of elder abuse and the need to protect this vulnerable population. In 1987, I served as Chief Counsel for the Pennsylvania Department of Aging during which time the Older Adults Protective Services law was passed and later led the group tasked with drafting and negotiating passage of the regulations implementing the Protective Services law.

When addressing the issue of how best to protect individuals suffering from Alzheimer's disease and other dementia-related illnesses or significant cognitive impairments, we must begin with the recognition that abuse, neglect and exploitation of the elderly is a societal issue that warrants a societal response. The Administration on Aging has stated that: "Every year an estimated 2.1 million older Americans are victims of elder abuse, neglect, or exploitation. And that's only part of the picture: Experts believe that for every case of elder abuse or neglect reported, as many as five cases go unreported."

Research studies have shown that older adults with dementia are at greater risk for abuse and neglect than those of the general elderly population. The Center of Excellence on Elder Abuse and Neglect at the University of California, Irvine summarized research in this area¹ and noted that three international studies found overall rates of abuse of people

¹ Center for Excellence on Elder Abuse and Neglect, "Fact Sheet, How at Risk for Abuse Are People with Dementia?" accessed on line August 7, 2013 at www.centeronelderabuse.org.

with dementia by their caregivers ranged from 34% to 62 %² and that a U.S. study found that 47% of caregivers surveyed engaged in abuse and neglect of people with dementia.³

I would like to focus my remarks on how to address these disturbing findings. Whether in the community or in a facility setting, the need to educate caregivers is critical. It has been my experience that those caring for adults with dementia are ill-equipped to recognize and respond appropriately to behaviors exhibited by individuals with dementia. Each individual suffering from a dementia-related disease is unique and the need for support will change over time as the disease progresses. Therefore, assessment and care planning that identifies issues and addresses them in a timely fashion is crucial to meeting the needs of residents of long-term care facilities.

Additionally, effective care planning includes respecting the legal concept of “informed consent” to guide the provision of services by including the resident and family members in the decision-making process. In the nursing home setting,

Residents have the right to be fully informed in advance about their care and treatment and of any changes in that care or treatment that may affect the resident’s well-being and... to participate in planning care and treatment or changes thereto.⁴

All too often, I have seen health care providers exclude residents and their families as well as direct care staff (e.g., certified nurse aides) from the care planning process. This failure has led to a lack of resident-centered approaches, non-compliant conduct by facility staff and a wholesale failure to meet the needs of residents with dementia.

Instead, without regard to legal requirements and clinical practices, antipsychotic medication has been administered to residents of nursing homes in response to behaviors that did not warrant this potentially harmful response. Recently, it was reported that 185,000 nursing home residents in US received antipsychotic medications contrary to regulatory requirements in 2010 and that greater than 1 in 5 nursing homes administer antipsychotics to a significant percentage of residents even though they do not have a

² Cooney, C., Howard, R., & Lawlor, B. (2006). Abuse of vulnerable people with dementia by their caregivers: Can we identify those most at risk? *International Journal of Geriatric Psychiatry*, 21, 564-571.
Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, G., and Livingston, G. (2009). Abuse of people with dementia by family caregivers: Representative cross sectional survey. *British Medical Journal*, 339(7694), 1-5.
Yan, E., & Kwok, T. (2010). Abuse of older Chinese with dementia by family caregivers: An inquiry into the role of caregiver burden. *International Journal of Geriatric Psychiatry*, doi:10.1002/gps.2561

³A. Wigglesworth, A, Mosqueda, L, Mulnard, R, et al. (2010), Screening for Abuse and Neglect of People with Dementia. *Journal of the American Geriatrics Society*, Volume 58, Issue 3, 493–500.

⁴ 42 CFR Sections 483.10 (b)(3),(4) and (d)(2).

psychosis or related condition.⁵ I believe that the root cause of this action lies in the fact that staff do not react appropriately to behaviors exhibited by residents and instead of addressing the underlying cause for the behavior they obtain an order for an antipsychotic medication. This conduct is not only non-compliant with federal regulations, it endangers older adults with a dementia-related illness. Those regulators tasked with enforcing regulatory requirements governing the prescribing of antipsychotic medication must take an aggressive approach to enforcement and accept only those plans of correction that address the root cause that led to the deficiency. A standard facility response must include meaningful staff education and competency evaluations in order to ensure that the underlying conduct is remedied.

In order to ensure that staff know how to respond appropriately to adults suffering from Alzheimer's disease or other dementia-related diseases, the state should mandate, as a condition of participation and payment in all state and federally-funded programs, training for all caregivers (whether they are located in a long-term care facility or are receiving benefits under state programs) that addresses, at a minimum, the following items:

- (1) Understanding dementia, including how the disease progresses and the difference between dementia and delirium;
- (2) Behavioral symptoms and how to address them without the need for medication (especially psychotropic medications);
- (3) Communication issues with residents with dementia;
- (4) Activities; and
- (5) Recognizing, assessing and treating pain.

I believe that caregivers do not typically set out to harm individuals for whom they are caring for but rather suffer from frustration when behavioral issues cannot be controlled. This frustration may lead to abusive or neglectful conduct by the caregiver which in turn causes physical and emotional harm to the older adult. It is my belief that a fully educated caregiver lessens the likelihood that abusive or neglectful conduct will occur. Moreover, the state has way too much money invested in the community and institutional caregiving business to allow this type of conduct.

Next, physicians, nurse practitioners and physician assistants must be educated regarding elder abuse identification and reporting as well. These health care professionals must know the signs and symptoms of abuse and neglect and feel comfortable reporting when there is reasonable cause to believe that such conduct is occurring. To that end, targeted education must be provided and mandated such that these professionals understand the societal interest in ending elder abuse. This training should be mandated as part of

⁵ Boston Globe, May 23, 2012;OIG Reports: "Medicare Atypical Antipsychotic Drug Claims for Elderly Nursing Home Residents" (May 2011); "Nursing Facility Assessments and Care Plans for Residents Receiving Atypical Antipsychotic Drugs" (July 2012).

medical and nursing education and integrated into continuing medical and nursing education requirements.

Additionally, older adult protective services workers and regulators from the Departments of Health (nursing homes) and Public Welfare (assisted living/personal care homes) who are charged with investigating abuse and neglect in the institutional setting need training on how to interview residents with dementia in order to ensure that valid complaints are not ignored based on alleged mental incapacities. A more standardized approach to evaluating the capacity of older adults should also be considered as part of improving the current response to reports of need.

Finally, we need to educate the public regarding elder abuse because only a community response to elder abuse will address this issue adequately. The state plays a critical role in preventing harm to adults with dementia by enforcing the Older Adults Protective Services Act. I believe that the state can do more. The Department of Aging should once again engage in a statewide public service campaign on how to identify and report suspected abuse, neglect and exploitation of older Pennsylvanians to the protective services agencies throughout Pennsylvania.

In the early 1990s, the Department of Aging assisted in the development of an award-winning public service announcement that aired statewide which was coupled with educational materials for distribution to the public. I believe that it is time has come to do such a campaign again. We need to educate the public to act if they suspect that an older adult is being victimized and cannot defend themselves based upon physical and/or mental impairments. We must have a system in place that stresses the need for the timely reporting of suspected elder abuse to the appropriate authorities, ensuring that an appropriate investigation is performed, and having a response that balances the rights of older adults to determine their care and treatment with the protections necessary to avoid an abusive or neglectful situation. This system must be available and functioning in the community and within institutional settings in order to successfully address elder abuse.

President John F. Kennedy told us years ago that "A society's quality and durability can best be measured by the respect and care given its elder citizens." Simply stated, we need to do more to prevent the victimization of some of our frailest members of our society and to eradicate elder abuse in order to fulfill this mandate.