

Pennsylvania Alzheimer's Disease Planning Committee Public Meeting
Minutes
July 15, 2013

Planning committee members in attendance

Chair - Secretary Brian Duke, Department of Aging

Legislative members

Geoffrey Mock for Senator Shirley Kitchen, Minority Chair of Senate Public Health and Welfare Committee

Senator Bob Mensch, Chair of Senate Aging and Youth Committee

Mike Deery for Senator Leanna Washington, Minority Chair of Senate Aging and Youth Committee

Representative Steve Samuelson, Minority Chair of House Aging and Older Services Committee

Representative Tim Hennessey, Chair of House Aging and Older Services Committee

Constituent representatives:

Dr. Carrie DeLone, Department of Health representative

Cynthia Lambert, Family member representative

Bonnie Rose for Cheryl Martin, Department of Public Welfare representative

George Gunn, Assisted Living representative

Susan Heinle, Homecare representative

Michael Ellenbogen, Person with AD representative

David Leader, Personal Care Home Industry

Robert Marino, Statewide Alzheimer's Association representative

Robin Mozely, Senior Care representative

Heidi Owen, Hospice representative

Maura Pelinsky

Dr. Charles Reynolds, Medical Care Provider Community representative

Pennsylvania Department of Aging Staff in attendance:

Terry Brown

Virginia Brown

Dr. Ken Brubaker

Amy Comarnitsky

Peg Glessner

Wilmarie Gonzalez

Ally Lush

Joyce O'Brien

Kelly O'Donnell

Steven Horner

Kellie Kask

David Prezner

Christina Reese

Carmen Toro

David Gingerich

Other PA Senators and Representatives in attendance:

Hal English

Keith Greiner

Steve Menton

Whitney Krosse

Bob Reilly for Congressman Scott Perry

Planning Committee members not in attendance:

Representative Matthew Baker, Chair, House Health Committee

Representative Florindo Fabrizio, Minority Chair of the House Health Committee

Beth Herold, Area Agency on Aging representative

Jill Schwartz, Caregiver representative

Dr. Stuart Shapiro, Nursing Facility representative

Dr. John Trojanowski, AD Researcher representative

Senator Pat Vance, Chair of Senate Public Health and Welfare Committee

Members of the public in attendance:

Donald Anklam

Noel Ballentine

James Barron

Jerry Brown

Aleshia Chacon

Susan Coleman

Stephanie Cornwall

Jeremy Darr

Cassie Darr

Jason Diley

Art DiLoreto

Frank J. Doutsuk(?)

Linda Myers Drie

Linda Drummond

Marjorie Dziennik

Bobbi Emanuel

Paul Eslinger

MaryAnn Garcia

Nicole Gear

Darren Haglen(?)

Tina Hess

Kristin Kingery

Leah Kithcart (Alzheimer's Association)

Tom Kloss

Dan Lago

Brian Long

Jim Millar

Steve Niebler
Joyce O'Brien
Judy Patrick
Bob Reilly
Lisa Salley
Pop Shenian
Joan Stakem
Margaret Stohler
Kevin Tucker (Alzheimer's Association)
Augusta Wargo
Robert Wargo
Stu Wesbury (PCOA)
Norma Gotwalt (PCOA)

Minutes prepared by Carmen, Lisa J. Bain

- I. Welcome: Secretary of Aging Brian Duke, Chair, welcomed participants to this first regional meeting of the Alzheimer's disease planning committee.
 - a. The plan for this meeting is to share information and update the public on our workgroups, and more importantly to listen to concerns of the public. Finally we will talk about next steps.
 - b. After lunch, committee members will reconvene for a short follow-up meeting.
 - c. Showed video from the Alzheimer's Association that provides background on AD and outlines the challenges we face.
 - d. Secretary Duke discussed the reasons for this group: The incidence of AD is rising in line with aging population. Committee has been tasked with developing a comprehensive state plan of action to address the growing crisis of AD and related dementias (ADRD) and complete this by Feb, 2014. In PA, an estimated 400,000 citizens are living with AD. PA Department of Health estimates over 35,000 deaths in PA have been caused by AD over a 10-year period. The cost of caring for those with AD nationally is estimated at over \$200 billion. Impact on unpaid caregivers also needs to be considered. These statistics show what we are facing. We must first understand the enormity of the crisis. We look forward to hearing from the public.

Solutions will come from many sectors – public, private, etc. Our committee's charge of the next 7 months – examine needs, research trends, study existing resources in PA, develop an effective response strategy to the rising numbers of those living with ADRD, and deliver final recommendations to Governor Corbett.

- II. Three workgroups created to address the many topics. Brief updates from these WGs:
 - a. WG # 1 – Prevention and outreach (Steve Horner). Our first meeting will be July 18. Goal of this group is to increase awareness of AD among the public; study existing resources for addressing needs of families and persons with AD; better

inform, educate, and equip the public and health care providers about AD; provide recommendations to assist unpaid caregivers, promote activities that would promote and improve brain health, improve public safety and address safety related needs; provide recommendations regarding legal protection of persons with AD, establish and maintain a clearinghouse of information, provide technical assistance and consultation to agencies about available resources, programs and services.

- b. WG #2 – Healthcare delivery (Heidi Owen). Charge is to increase detection and diagnosis, improve individual health care received by persons with AD, expand the capacity of the healthcare system to meet the needs of the growing numbers of persons with AD, and increase services. Also charged with developing strategy to mobilize the Commonwealth's response to the anticipated increase in incidence of AD. Will also address workforce issues, home- and community-based services, social and cultural diversity, finances, palliative care, medical home, Accountable care organizations, technology and telemedicine, bioethics, and dementia friendly communities. We had first conference call on June 28. Chairperson- Heidi Owen.

We decided we would review and condense our goals prior to bringing advisors on. We are collecting names and credentials of advisors. Next teleconference on 8/6/13.

- c. WG #3 – Research and Metrics (Brian Duke). Goal is to look at improving quality of info available. Also we will look at research results available and implications on public health; data that informs us about delivering care and support more cost effectively (including technological solutions); how we collect and analyze data and where is it stored; recommendations on how government adopts policies to assist people and families; how to address economic issues including impact on individuals and caregivers as well as the Commonwealth; grants and funding opportunities. WG met on July 10, chair has not been selected yet. Will be reviewing national plan and other state plans.

We welcome additional recommendations of advisors.

III. Public comments – some people have signed up; if you would like to speak but have not signed up, please speak to Amy.

- a. Dr. Noel Ballentine, Hershey Medical Center. A geriatrician for 30 years. Need to improve geriatrics workforce. Number of elders has doubled in past 30 years. Will double again by 2050. Geriatrics is the least populated specialty in medicine. There are 208,000 people over age 60 per geriatrician in the U.S. Role of geriatrician will be to take care of the most complicated and frail elders and teach other primary care physicians how to care for elders. I'm convinced that nurses can take care of 80-90% of geriatric issue, sometimes far better than physicians. Another important issue – caring for elderly patients with AD who have

psychiatric issues. We need more geriatricians, need to incentivize people to go into geriatric medicine.

- b. Kristin Kingery – LSW has worked with people with dementia for 30 years and volunteer for Alzheimer's Association for 20 years. Shared a story of Ed and Mary who came to her support group. Mary had dementia, Ed did not, but like many caregivers, he became depressed and did not take care of his own health. He died before Mary at the age of 65.
- c. Pop Shenian, Association for Frontotemporal Degeneration. FTD is early onset dementia that affects patients in 50s and 60s, sometimes even earlier (prime earning years), affecting behavior, memory and speech. We ask committee to remember FTD in the related dementias area. It is frequently misdiagnosed, leading to inefficiencies and inappropriate treatment and support.
- d. Joyce O'Brien, has worked in LTC for over 40 years; also has 83 year old mother-in-law with AD who lives in a nursing home. Joyce told a story about visiting her and taking her for a drive. Later in the day, she had no memory of the visit. One of most valuable lessons family members need to learn about AD is that is as difficult as it may seem, "experience tells me it is not all that important if mom doesn't recognize you... families have to learn to separate our wants from Alzheimer's victims' challenges..." Support groups can enable us to share stories and coping skills.
- e. Linda Myers Drie, daughter of a father with AD. Told his story – he was diagnosed in 2010 and was prescribed Aricept. Neurologist was not helpful; Linda says she learned more from her veterinarian than she did from the neurologist! Mother developed esophageal cancer and Linda left the workforce to care for her parents. Faced challenges trying to get caregivers to come into the home. Father put in nursing home but wandered off after 4 days. He was hospitalized, fell, and had to have hip surgery. Hospital unable to handle AD; no geriatric psychiatrist available. Message: training needed for professionals on how to talk to AD patients and their families and how to treat AD patients.
- f. Stu Wesbury, resident of Willow Valley Retirement Community and Vice Chair of Pennsylvania Council on Aging (PCOA). PCOA pledges support for the committee.
- g. Lisa Salley, family member. Father had Lewy Body Dementia (LBD), which is essentially a combination of AD and Parkinson's (PD) that affects younger persons. My mother gave her life attempting to care for my father; she died at age 66 from diabetes, exacerbated by caring for my father. I assumed responsibility for caring for my father – gave up my career, moved back to Philly, etc. Aunt also died from AD just a few days before her father died. Lisa raised a number of issues:
 - i. Keep in mind the face of the disease and families in crisis now.
 - ii. Families in middle income brackets do not qualify for help nor do they earn enough to pay for care.
 - iii. Adult day care not prepared to handle someone with early onset AD; should be able to support AD across entire spectrum of disease. Lisa's family was able to create structure at home through a hodge-podge of services (VA, private pay, etc.).

- iv. Difficult to find the right doctors who would engage with us as a family and treat other doctors like colleagues irrespective of the institution with which they were affiliated.
- v. Too many people in hospital that were not knowledgeable; we worked around by always having a family member or friend with him.
- vi. Committee should seize the economic opportunity that AD presents: research, biotech, become a hub for research and research solutions.
- vii. Training, standards, and adequate funding need to be in place for service providers.
- viii. Top 3 challenges – 1) accessible help for all economic levels and to enable person to stay at home, 2) knowledge basis of medical professionals, 3) cultural sensitivity (socioeconomic factors as well as race and ethnicity).
- h. Jim Millar, wife was diagnosed 6 years ago at age of 44. We have young children. Got support from Alzheimer's Association, nothing from the Dept of Aging. Consider that this affects young people as well as elders.
- i. Tina Hess, board member of PA Adult Day Services Association and CEO of Good News Consulting. PADSAs asked me to share letter from daughter of a man who was diagnosed with dementia and PD at the age of 55 and received adult day services at Landis Homes Adult Day Services in Lancaster. “Dad experienced an almost rebirth... thrived in the environment.” Committee should remember adult day services when considering options for care.
- j. Keith Greiner, PA State Representative (43rd district). People need to be educated on statistics about aging. PA has one of the oldest populations in the country. This problem will take a huge economic investment. Need to all work together to minimize the impact of AD.
- k. Susan Coleman, family caregiver for 89 year old mother who had vascular dementia. Caregiver support meetings were saving grace over last 4 yrs 8 months. Caregiving stress and financial stress have been overwhelming. Susan’s husband added that legislature should consider tax credit for caregivers (if caregivers get paid, the wages are taxable). Need some kind of incentives for caregivers to keep family members at home. Someone else added that gifting laws might be modified to enable more money to be transferred tax-free to family caregivers.
- l. Dr. Ken Brubaker, PA Dept of Aging. Geriatrician by training and son of two parents who died of dementia (vascular and AD). My concern is with workforce. My observations: 1) lack of skills in diagnosing AD in the medical professions, 2) inappropriate use of medication, 3) Residents who have no decision making capacity and are not being referred to Adult Protective Services, 4) Denial by family members, 5) Caring for AD requires caring for the family as well as the person affected, 6) There are no medications approved for behavior problems in individuals with AD, 7) I have reviewed many cases of abuse – most often these are cases are due to lack of training.

Med students have little or no exposure to geriatrics. This needs to be expanded and we need to be creative, incentivizing with debt reduction to encourage more to go into geriatrics? In Lancaster, we have family practice trainees rotate through

geriatrics. Regarding early AD patients – this is a very important group although a small minority. Geriatricians are trained to diagnose early AD.

- m. Donald Anklum, Elder Health Services. Works with disenfranchised folks in health care. Today want to talk about older LGBT adults. Access to care is severely limited. Institutions not culturally competent, stigmatizing, etc. Estimated that 75% of LGBT elders live alone, 90% do not have children, and they lack the social structures that other elders have. LGBT individuals are often caregivers for their aging parents. We ask committee to take steps to ensure all Pennsylvanians have equal, safe access to culturally competent care and services by the year 2020.
 - n. Hal English, PA Representative from Allegheny County and a practicing attorney in elder law. People who are caregivers to their parents – issues may come up with regard to wills and estates.
 - o. Jason Diley, CEO of the Ross Estate, a not-for-profit organization in Warren County. Challenge committee – People with AD who have higher ADL score have difficulty getting resources they may deserve. These people need more resources and staff need more training. Keep rural facilities and populations in mind when making decisions.
 - p. ? speaker – clear need for improvements to infrastructure. People generally feel better and do better in their homes. Thanks to everyone for efforts to find solutions.
 - q. Kevin Tucker, board member of Greater PA chapter of Alzheimer's Association, and chairman of public policy coalition. The Association is the 3rd largest supporter of AD research. People who wish to be advocates can sign up on our website and to large and small things, such as sending letters to your legislators.
- IV. Wrap up – Secretary Duke. Thanks to all who came today especially those who shared their stories. We heard the call to develop professionals in the field, about the importance of supporting our caregivers, about related dementias, about the importance of education for all who provide care, about the health of the caregiver and impact on the health of the caregiver caring for someone with AD, about experiences and what needs to be looked at in different parts of the continuum of care (hospital, assisted living, personal care home, nursing home), about the need for accessible services, the knowledge of professions among professions in terms of delivering services, the need for cultural sensitivity (African American, LGBT, socioeconomic), also about service delivery from the standpoint of the provider.
- a. Secretary asks for comments on format – Lisa suggested a panel discussion to have more exchange, less repetition, getting to next level of discussion.
 - b. Another speaker agreed that a panel discussion would be great.
- V. Next steps
- a. Next regional meeting August 8th in State College, August 13th in Scranton, August 15th in Philadelphia, September 16th in Clarion with a specific focus on living with Alzheimer's in rural communities, September 17th in Pittsburgh.

- b. Directions and news will be available on the website, www.aging.state.pa.us. WGs will run concurrently with regional meetings.
- c. Committee will regroup in the fall in Harrisburg to develop a framework with the objective of having a final plan completed by February, 2014.
- d. We will collect public input from these meetings as well as through other means, best to get comments to us by September/October, although we will take comments through February. Interested parties are encouraged to provide feedback through the website, by phone, 717-425-5115, or by mail: 555 Walnut St., 5th floor, Harrisburg, PA 17101-1919. In addition we have developed a tool with the Alzheimer's Association to collect feedback. This is available on the website as the Alzheimer's Disease Survey.