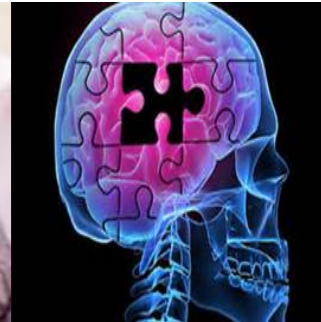
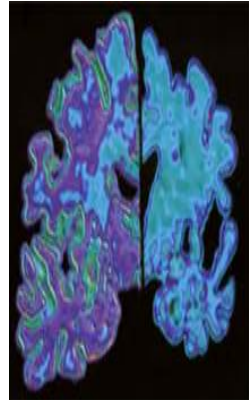


State Plan on Alzheimer's Disease and Related Disorders

June 24, 2014



▶ Background:

- On February 7, 2013, Governor Corbett signed Executive Order 2013-01 establishing the Alzheimer's Disease Planning Committee comprised of 26 members and was given the charge:
 - ✓ To examine the needs and research the trends in the Pennsylvania's Alzheimer's population;
 - ✓ To study existing resources for addressing the needs of persons with Alzheimer's disease, their families and caregivers;
 - ✓ To develop a strategy to mobilize the commonwealth's response to the anticipated increase in incidence of Alzheimer's disease in Pennsylvania;
 - ✓ To submit recommendations to the Governor by Feb. 7, 2014.
- The committee was a robust group with varied backgrounds and comprised of: a Pennsylvanian living with Alzheimer's disease; representatives of families and caregivers of persons living with Alzheimer's disease and other disorders; providers from across the aging community; elected officials; and leading researchers from University of Pennsylvania and University of Pittsburgh's Institutes on Aging.
- Three workgroups were established to address major issues confronting the commonwealth:
 - Prevention and Outreach; Healthcare Delivery and Workforce; and Research and MetricsThe workgroups were instrumental in developing a set of recommendations, goals and strategies that were compiled into the overall seven recommendations.

▶ Background continued:

- In June 2013 – the committee kicked off workgroups.
- From July through September 2013 – the committee held regional public meetings in Harrisburg, State College, Scranton, Philadelphia, Clarion, and Pittsburgh to receive input about the needs and resources for Alzheimer’s disease.
- Over 100 Pennsylvanians testified at these six regional meetings and over 330 comments were received through an online survey (offered through the Alzheimer’s Association), correspondence and comments offered at five full committee meetings.
- From October 2013 through January 2014, committee meetings were held to draft and finalize the report.
- On June 12, 2014, the Alzheimer’s Disease and related Disorders State Plan was approved by Governor Corbett.

▶ Recommendations

- Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of Alzheimer's disease and related disorders (ADRD) across the commonwealth.
- Due to the magnitude of the ADRD crisis, identify and, where possible, expand financial resources available to implement this plan through federal, state, foundation, private, and other innovative funding mechanisms and partnerships.
- Promote brain health and cognitive fitness across the life cycle from birth onward.
- Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis through end-of-life care.
- Enhance support for family and non-professional caregivers and those living with ADRD.
- Build and retain a competent, knowledgeable, ethical, and caring workforce.
- Promote and support novel and ongoing research to find better and effective cures, treatments, and preventive strategies for ADRD.

➤ Recommendation #1

Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of Alzheimer's disease and related disorders (ADRD) across the Commonwealth.

- Determine baseline and outcome data regarding the prevalence and demographic characteristics of Pennsylvanians with ADRD, including age of onset, comorbid conditions, prevalence of risk factors, use of medications, and health inequities and disparities.
- Determine the economic impact of ADRD on Pennsylvania.
- Reduce the stigma associated with ADRD by raising dementia awareness and knowledge among the public with key message that living well with dementia is an attainable goal.
- Raise ADRD awareness and knowledge among health-care providers, public health professionals, and aging services providers.
- Improve information sharing regarding treatment and prevention options (including the goals discussed in recommendation #3) for ADRD with residents of Pennsylvania to improve quality of life and patient outcomes.

➤ Recommendation #1

Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of Alzheimer's disease and related disorders (ADRD) across the Commonwealth.

- Promote and support the development of dementia friendly communities to empower individuals with dementia and their caregivers and combat stigma.
- Improve the safety of individuals with ADRD in communities across the commonwealth.
- Protect individuals with ADRD from abuse and financial exploitation using recent guidance from key federal and state agencies.
- Convene annual PA Alzheimer's Plan Summit meetings to evaluate progress of the Plan, strengthen partnerships, build community support for the Plan, recognize excellence, and identify next steps.

➤ Recommendation #2

Due to the magnitude of the ADRD epidemic, identify and where possible expand financial resources to implement this plan through federal, state, foundation, private, and other innovative funding mechanisms and partnerships.

- Review and maximize utilization of existing financial resources to ensure that individuals with ADRD receive care in the most appropriate and cost-efficient setting.
- Develop and/or promote programs to encourage research and technology development in the area of ADRD.
- Identify and implement innovative funding mechanisms to support research aimed at finding cures, treatments, and prevention strategies for ADRD.
- Develop collaborative public-private investments in awareness campaigns, education, services, and caregiver support.
- Advocate for increased federal support for ADRD research.

▶ Recommendation #3

Promote brain health and cognitive fitness across the life cycle from birth onward.

- Potentially delay the onset of ADRD by promoting brain health and cognitive fitness.
- Build capacity to promote brain health through partnerships among government agencies, patient advocacy organizations, health care systems, academic institutions, and payers (e.g., insurance companies and Medicare).

➤ Recommendation #4

Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis through end-of-life care.

- Assess the current strengths, gaps, and barriers within the continuum of care of each Pennsylvania county in its ability to support all individuals with ADRD and their caregivers.
- Develop a plan to address the identified gaps in the continuum of care, including, but not limited to, adult day services, palliative care, end-of-life care, transportation, private duty, respite care, and other home and community-based services.
- Expand availability of and access to care management services in order to coordinate services for individuals with ADRD living in settings across the continuum of care.

➤ Recommendation #4

Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis through end-of-life care.

- Increase the early detection and diagnosis of ADRD by promoting the assessment of cognitive health and depression.
- Improve quality of life, safety, and cost of care by maintaining individuals with ADRD in the most appropriate and cost-effective settings.
- Promote innovation in service systems and funding mechanisms related to the care of individuals with ADRD, including underserved populations and those in rural communities of the commonwealth, which improve quality of care and support, enhance quality of life, create efficiencies, and reduce costs.

➤ Recommendation #5

Enhance support for family and non-professional caregivers and those living with ADRD.

- Conduct an assessment of caregiver needs, including, but not limited to, legal and financial guidance, respite care, psychological counseling, and stress management.
- Provide resources and support that will better enable informal (i.e. non-professional) caregivers to care for their loved ones and themselves.
- Address the unique needs of those living with ADRD.
- Provide training and education for non-professional caregivers and those living with ADRD.

➤ Recommendation #6

Build and retain a competent, knowledgeable, ethical, and caring workforce.

- Educate physical and behavioral health care professionals at all levels of care about the unique needs of persons with ADRD.
- Encourage professionals to pursue and remain in careers in ADRD care.

▶ Recommendation #7

Promote and support novel and ongoing research to find better and effective cures, treatments, and prevention strategies for ADRD.

- Promote participation in clinical trials, ensuring inclusion of underserved and rural populations.
- Promote Pennsylvania as a magnet for clinical research by developing a network of hospital and other health care providers with clinical research capability across the commonwealth.
- Cultivate collaborative efforts of the research, clinical, pharmaceutical, regulatory, and payer communities to identify barriers and solutions at each stage of treatment development with the goal of producing novel methods to prevent and treat ADRD.
- Provide incentives for biomedical technology companies working in the ADRD field to remain in or relocate to Pennsylvania.

Next Steps

- Reconvene the Alzheimer's Disease Planning Committee Members
- Examine additional ways to implement the plan
- Develop training on ADRD for transportation providers, EMS providers and first responders to identify and assist individuals with ADRD
- Institute revisions to the Level of Care Assessment process to more fully identify individuals with ADRD
- PACE Academic Detailing
- Continue to educate caregivers on support services for families and those living with ADRD



QUESTIONS?

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