THE IMPACT OF ALZHEIMER’S DISEASE AND THE POLICY RESPONSE TO THIS CHALLENGE

ALZHEIMER’S FOUNDATION OF AMERICA
What Is AD?

• Not normal aging
• A fatal, irreversible, progressive brain disorder
• Common symptoms include:
  – Memory loss
  – Confusion
  – Spatial disorientation
  – Lack of judgment
  – Inability to communicate
What Is AD?

• Over a period of years, the disease leads to:
  – the complete loss of cognitive function
  – a long period of dependency
  – ultimately, death
Incidences of AD

• As our nation ages, the number of people with AD is expected to triple in the next 40 years
• Researchers project that the total number of people with Alzheimer’s dementia in the United States in 2050 will be 13.8 million, up from 4.7 million in 2010
• About seven million Americans with the disease will be 85 or older
Incidences of AD

• AD is the third leading cause of death in the US
  – Rush Institute Study
    • AD vastly underreported
    • CDC reports only 90,000 deaths a year attributable to AD
    • Study indicates more than 500,000

• Only growth category in the top ten causes of death in the US

• Only condition with no cure or treatment to reverse or slow its progression
Costs of AD

- As the incidence of Alzheimer’s grows, care costs are skyrocketing
- A 2013 RAND study of adults aged 70+ found that the total economic cost of dementia in 2010 was $109 billion for direct care—higher than heart disease and cancer; and $159 billion to $215 billion when cost of informal care is included
Costs of AD

• In 2012, the direct costs of caring for people with AD to American society totaled an estimated $200 billion, including $140 billion in costs to Medicare and Medicaid

• These costs will soar to a projected $1.1 trillion (in today’s dollars) by 2050

• This dramatic rise includes a 500 percent increase in combined Medicare and Medicaid spending
Federal Response

• On January 4, 2011, President Barack Obama signed into law the National Alzheimer’s Project Act (NAPA)
  – Required HHS the to establish the National Alzheimer’s Project to:
    • Create and maintain an integrated national plan to overcome Alzheimer’s disease
    • Coordinate Alzheimer’s disease research and services across all federal agencies
    • Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer’s disease
    • Improve early diagnosis and coordination of care and treatment of Alzheimer’s disease
    • Improve outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer’s disease
    • Coordinate with international bodies to fight Alzheimer’s globally
Federal Response

• Establishes the Advisory Council on Alzheimer’s Research, Care, and Services (Advisory Council)

• HHS, in collaboration with the Advisory Council, to create and a national AD plan
  – Plan includes performance metrics
  – Updated annually
NAPA Plan

• In May 2012, HHS unveiled National Plan to Address Alzheimer’s Disease to:
  – addresses the major challenges presented by Alzheimer’s disease
  – outline and track the various goals and activities—from advancing scientific collaboration to improving patient care—now undertaken with increasing collaboration between the public and private sectors
NAPA Goals

NAPA plan has five overarching goals:

• Goal 1 - Prevent or Effectively Treat Alzheimer’s Disease by 2025
• Goal 2 - Enhance Care Quality and Efficiency
• Goal 3 - Expand Supports for People with Alzheimer’s Disease and their Families
• Goal 4 - Enhance Public Awareness and Engagement
• Goal 5 - Improve Data to Track Progress
AFA Response

• Appropriations
  – “Double Down” on AD research funding at the National Institutes of Health (NIH)
    • NIH is largest federal funder of AD research
    • Current spending on AD research is approximately $550 million in FY ’14
    • Compared to $6 billion will for cancer research; $3 billion for HIV/AIDS; $2 billion for cardiovascular disease; $1.3 billion for heart disease; and more than $1 billion for diabetes
  – Chronic underinvestment and flat federal funding research leaves promising AD research unfunded and slows scientific progress
AFA Response

• **Clinical Care**
  – Support expansion of coordinated care delivery models, transitional care programs, and expanded caregiver supports
  – AFA’s Cost of Care Report:
    • Financial analysis of caregiving provisions in NAPA plan
    • Implementation of these care models will provide significant cost savings – over $110 billion over 10 years - while promoting better health outcomes
    • Such models and expansion of caregiver training and supports avoids unnecessary hospitalizations, emergency room visits while providing tools to caregivers that delay nursing home placement and allow those with AD to age in place for a longer period
AFA Response

• Clinical Care (cont’d)
  – Support need for timely and accurate diagnosis
    • Early detection of AD can allow for greater care management
    • Allows individual to be more involved in care choices
  – Cognitive screens part of Medicare’s annual wellness exam
  – AFA’s Nat’l Memory Screening Day (NMSD)
    • AFA offers free, confidential memory screenings at over 2000 sites across the country
    • Promoting awareness of AD and overall brain health
    • This year’s NMSD is Tuesday, November 18th
AFA Response

• Long Term Care Services and Supports
  – Establish a Medicare home health benefit for AD
  – Reauthorize the Older Americans Act
  – Establish an adult day services option under Medicare
  – Establish a palliative care benefit for those with AD
  – Increase dementia care training for both direct and family caregivers
  – Expanding tax credits for family caregivers
AFA’s Response

• AD Drug Development
  – Facilitate the establishment and standardization of biomarkers
  – Compress regulatory pathways for promising drugs
  – Expand coverage for amyloid PET imaging
  – Support international research efforts
  – Support clinical trial outreach:
    • Establish patient registries
    • Address issues of consent for individuals with AD
    • Target outreach to minority populations
  – Support innovative public/private partnerships
State Response

• Over 42 states and the District of Columbia have, or are in the process of finalizing, state Alzheimer’s plans
  – NY State Plan
    • Comprehensive
    • David Hoffman, Director of the Bureau of Chronic Disease Prevention and Control, NY State Department on Aging sits on the NAPA Advisory Board and chairs, LTSS Subcommittee
State Response

• Why are state plans needed:
  – Can be specifically tailored to state demographics and the Alzheimer’s disease population in their state
  – Can target local resources
  – Provide services and benefits not controlled by federal health programs (like Medicaid)
  – Controls ability to license and certify care workers and facilities
  – Administers Administration on Aging programs (like respite care, adult day services, meals-on-wheels, etc.)
  – Can influence workforce development curriculum
  – Administers law enforcement and first responders
  – Has jurisdiction over elder care cases and other legal issues
State Response

- What makes successful state plans?
  - Broad buy-in from Governor, State House and community stakeholders
  - Recommendations that are local in scope and achievable in scale
  - Making the plan culturally sensitive
  - Continually updating the plan and its recommendations including charting progress of implementation
Questions?

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