



**STATE OF TENNESSEE
COMMISSION ON AGING AND DISABILITY**

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February 12, 2009

The Honorable Phil Bredesen
Governor of Tennessee
Tennessee State Capitol
Nashville, Tennessee 37243-0001

Dear Governor Bredesen,

Attached, please find the final report of the Alzheimer's Disease Task Force which was established by the General Assembly of the State of Tennessee. The Alzheimer's Disease Task Force was directed to assess the current and future impact of Alzheimer's disease on Tennesseans; to examine the existing industries, services and resources addressing the needs of persons with Alzheimer's, their families, and caregivers; and to develop a strategy to mobilize a state response to this public health crisis.

We appreciate the opportunity to work with the Alzheimer's Disease Task Force and look forward to our continued relationship with the Task Force as, together, we begin to carryout the plans and recommendations.

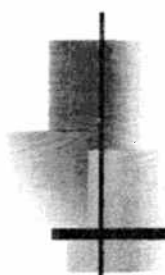
Sincerely,

A handwritten signature in cursive script, appearing to read "Mike Hann".

Mike Hann
Executive Director

cc The Honorable Ron Ramsey, Lieutenant Governor and Speaker of the Senate
 The Honorable Kent Williams, Speaker of the House of Representatives
 The Honorable Rusty Crowe, Chair, Senate General Welfare, Health and Human
 Resources
 The Honorable Joe Armstrong, Chair, House Health and Human Resources
 Russell Humphrey, Chief Clerk of the Senate
 Burney Durham, Chief Clerk of the House

MH/kz



Tennessee Alzheimer's Disease Task Force Final Report

Presented to
Phil Bredesen, Governor
and the
Tennessee General Assembly
February 15, 2009

Prepared by
Tennessee Commission on Aging and Disability
Mike Hann, Executive Director

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Alzheimer's Disease Task Force Members

Representative Joe Armstrong

Senator Rusty Crowe

Representative Mike Harrison

Senator Roy Herron

Jeff Beaty, Serenity Health Care

Luke Gregory, Tennessee Association of Homes and Services for the Aging

Ruthann G. Shelton, Tennessee Association of Adult Day Services

Sheryl Lukeke-Smith, Horizon Bay Retirement Living

Janice Wade-Whitehead, East Tennessee chapter of Alzheimer's Association

Tracey Kendall, Northeast/Southeast chapter of Alzheimer's Association

John Mayo, person with Alzheimer's Disease

Herbert Ann J. Krisle, Caregiver

Dr. Richard Lane, Vanderbilt Medical Group

Dr. Randy D. Blakely, Vanderbilt University School of Medicine

DEDICATION

Thank you to the many people who helped in the development of this report and a special thank you to those individuals and families who have lived through or are living through the devastation of Alzheimer's disease. It is the hope of this Task Force that implementation of the recommendations will result in providing the assistance needed by individuals and families to deal with this devastating disease.

Governor Phil Bredesen and the General Assembly
who enacted the Legislation establishing the Alzheimer's Disease Task Force

Every person who attended the Public Forums

Community Members who participated on the Task Force Workgroups

Tennessee Commission on Aging and Disability

Area Agencies on Aging and Disability

Eastern Tennessee and the Mid-South Chapters of the Alzheimer's Association

Tennessee Association of Adult Day Services

Tennessee Medical Association

Tennessee Department of Health

Tennessee Department of Mental Health and Developmental Disabilities

Tennessee Hospital Association

Tennessee Respite Coalition

Tennessee Department of Finance and Administration

Tennessee Health Care Association

Executive Summary

Alzheimer's is a devastating disease that directly impacts the individual, the family, the community, and the nation – physically, emotionally, spirituality, and financially. With the aging of the “baby boomers”, a significant increase in Alzheimer's disease is anticipated.

Therefore, under Public Chapter No. 566/Senate Bill No. 826, the Tennessee Alzheimer's Disease Task Force was created effective July 1, 2007, “the public welfare requiring it.” To address the anticipated increase in Alzheimer's disease the Task Force was “directed to assess the current and future impact of Alzheimer's disease on Tennesseans; to examine the existing industries, services and resources addressing the needs of persons with Alzheimer's, their families, and caregivers; and to develop a strategy to mobilize a state response to this public health crisis.”

Although the task seemed overwhelming given the impact of the problem and length of time in which to develop the recommendations, the Task Force members began their deliberations and fact finding in an effort to develop the strategy as requested. The recommendations contained in this report are the result of the knowledge and insight gained through the personal and professional expertise brought to the Task Force by its members; input and presentations provided by individuals and groups with knowledge of the disease and its impact, such as the Tennessee Commission on Aging and Disabilities (TCAD) and the Area Agencies on Aging and Disabilities (AAAD), Tennessee Department of Health (TDOH), Tennessee Department of Mental Health and Developmental Disabilities (TDMHDD), and TennCare; Alzheimer's Association (AA) and the testimonials provided by the citizens of Tennessee through Public Forums held throughout the State formed the basis of this report to the Governor and the General Assembly.

Task Force members recommend the following strategies be undertaken in no specified order within the next 1-3 years (Phase 1). The information in parentheses indicates the location of the recommendation with action steps in the body of the document.

- Develop a comprehensive infrastructure for Alzheimer's disease and related dementia (ADARD) through the Tennessee Commission on Aging and Disability. (Section 1: Infrastructure: Recommendation I)
- Improve access to adult day programs, respite and homemaker services, assisted living, transportation and other community-based services. (Section 1: Infrastructure: Recommendation II)
- Establish an effective, coordinated and comprehensive surveillance system or enhance the current surveillance and epidemiology system to include Alzheimer's disease and related dementia. (Section 2: Data: Recommendation I)

- Strengthen training in geriatrics, especially dementia training, for all health professionals including physicians, nurses, other allied professionals and other members of the medical community. (Section 3: Education and Training: Recommendation II)
- Increase and enhance training on Alzheimer's disease and related dementia for various stakeholders. (Section 3: Education and Training: Recommendation IV)
- Educate caregivers through the Alzheimer's Association and other agencies, provide support, and possible referral to mental health services, paying attention to caregiver's mental state during office visits. (Section 3: Education and Training: Recommendation V)
- Increase and improve support, counseling and education for family and informal caregivers to provide information on available support services and the importance of maintaining their own health. (Section 4: Services and Facilities: Recommendation III)
- Ensure access to affordable health coverage for Alzheimer's disease and related dementia and mental health issues from the private sector and those not eligible for government funding. (Section 5: Health Coverage and Funding: Recommendation I)
- Ensure that Adult Protective Services and Guardianship services are adequately funded to meet the needs of vulnerable adults. (Section 5: Health Coverage and Funding: Recommendation IV)

Task Force members recommend the following strategies be undertaken in no specified order within the next 4-7 years (Phase 2). The information in parentheses indicates the location of the recommendation with action steps in the body of the document.

- Provide access to affordable transportation options in all areas of the State, urban and rural. (Section 1: Infrastructure: Recommendation III)
- Develop driving guidelines for persons with dementia. (Section 1: Infrastructure: Recommendation IV)
- Enhance and strengthen the infrastructure to provide a continuum of care for persons with Alzheimer's disease and related dementia and their caregivers to address the progression of the disease from mild to severe and to allow flexibility to move within the care system depending on the needs of the persons with Alzheimer's disease and related dementia and their families. (Section 1: Infrastructure: Recommendation V)
- Encourage awareness of elder care law and access to attorneys with training in elder care law. (Section 1: Infrastructure: Recommendation 6)

- Educate physicians and other health care professionals to improve accurate diagnosis and appropriate treatment and referrals as early in the disease process as possible. (Section 3: Education and Training: Recommendation I)
- Establish or enhance policies, procedures and incentives to incorporate evidence-based practices into training, service and program activities. (Section 3: Education and Training: Recommendation III)
- Develop a multi-disciplinary approach in partnership with the Tennessee Hospital Association and Tennessee Medical Association to address Alzheimer's disease and related dementia in the hospital setting to enhance the well-being and safety of the individual. (Section 4: Services and Facilities: Recommendation I)
- Partner with the Tennessee Department of Health and the Division of Health Care Facilities to review current dementia related regulations such as the full disclosure regulation and how these regulations are being implemented and enforced. (Section 4: Services and Facilities: Recommendation II)
- Encourage the State to explore alternative programs of care, especially for elderly with dementia. (Section 4: Services and Facilities: Recommendation IV)
- Provide support and assistance to the rapidly increasing numbers of Tennesseans and their families with Alzheimer's disease and related dementia who are above the poverty level by providing a wide array of home and community based services based on a sliding fee scale. (Section 4: Services and Facilities: Recommendation V)
- Provide access to basic clinical evaluation(s) including help for families and informal caregivers, in relation to ongoing case management. (Section 4: Services and Facilities: Recommendation VI)
- Provide options to increase insurance coverage for persons with Alzheimer's disease and related dementia. (Section 5: Health Coverage and Funding: Recommendation II)
- Develop a plan to provide funding to individuals and/or facilities that are engaged in research on Alzheimer's disease and related dementia. (Section 5: Health Coverage and Funding: Recommendation III)

Task Force members recommend the following strategies be undertaken in no specified order within the next 8-10 years (Phase 3). The information in parentheses indicates the location of the recommendation with action steps in the body of the document.

- Enhance and strengthen the infrastructure to provide a continuum of care for persons with Alzheimer's disease and related dementia and their caregivers to address the progression of the disease from mild to severe and to allow flexibility

to move within the care system depending on the needs of the persons with Alzheimer's disease and related dementia and their families. (Section I: Infrastructure: Recommendation V)

Following a history of the work and process of the Task Force and background information and data on Alzheimer's disease, the recommendations have been divided into five (5) sections based on the efforts of the three workgroups into which Task Force members were divided and the issues reported during the Public Forums. The testimony of the individuals who attended the forums reflect the frustrations, the emotions, the needs, and the wishes of the persons who are personally experiencing or have personally experienced the impact of Alzheimer's disease on their own lives and families. (See Appendix 4)

The recommendations contained within this report are not all inclusive and do not address all of the identified issues; however, the Task Force has attempted to include those issues which can be realistically addressed and move the strategies forward.

Task Force History and Process

The Tennessee Alzheimer's Disease Task Force (TADTF) was established by the General Assembly of the State of Tennessee, effective July 1, 2007, pursuant to Public Chapter No. 566, an act to amend Tennessee Code Annotated, Title 4; title 33; Title 68 and Title 71, relative to Alzheimer's disease. (Appendix 1) The membership of the Task Force was defined in the legislation. Membership shall include the chairs of the Senate General Welfare Committee and the House Health and Human Resources Committee or their designees; one member of the Senate to be appointed by the Speaker of the Senate; one member of the House of Representatives to be appointed by the Speaker of the House of Representatives; at least one person with Alzheimer's disease; one caregiver of a person with Alzheimer's disease, and representatives of the Tennessee Health Care Association, Tennessee Association of Homes and Services for the Aged, Tennessee Association of Adult Day Services, medical care provider community, Mid-South Chapter of the Alzheimer's Association, Eastern Tennessee Chapter of the Alzheimer's Association, and Northeast/Southeast Tennessee Chapter of the Alzheimer's Association; and an Alzheimer's disease researcher. Non-legislative members of the Task Force were appointed by Governor Phil Bredesen.

Goals of the Task Force

The goals of the Tennessee Alzheimer's Disease Task Force, as stated in the legislation, were as follows:

- To assess the current and future impact of Alzheimer's disease on Tennesseans;
- To examine the existing industries, services and resources addressing the needs of persons with Alzheimer's, their families, and caregivers;
- To develop a strategy to mobilize a state response to this public health crisis;
- To hold public meetings and utilize technological means, such as web casts, to gather feedback on the recommendations from persons and families affected by Alzheimer's disease and the general public; one public hearing will be conducted in each of the state's three grand divisions and the primary purpose of such public hearings shall be the receipt of public testimony relevant to the task force's assigned topics of inquiry;
- To submit a progress report of its findings to the general assembly no later than February 15, 2008; and
- To submit a report of findings and date-specific recommendations, including any suggested legislation, to the general assembly and the governor in the form of a State Alzheimer's plan no later than February 15, 2009.

The Tennessee Alzheimer's Disease Task Force included an examination of the following in its assessment and recommendations:

1. Trends in and needs of Tennessee's Alzheimer's population as well as how this population with dementia is changing, including, but not limited to:
 - a. State role in long-term care, family caregiver support, and assistance to persons with early-stage and young onset of Alzheimer's; and
 - b. State policy regarding persons with Alzheimer's and related dementia*.
2. Existing services, resources, and capacity, including, but not limited to the:

- a. Type, cost and availability of dementia services;
 - b. Dementia-specific training requirements for long-term care staff
 - c. Quality care measures for residential care facilities;
 - d. Capacity of public safety and law enforcement to respond to persons with Alzheimer's;
 - e. Availability of home and community-based resources for persons with Alzheimer's and respite care to assist families;
 - f. Inventory of long-term care dementia care units;
 - g. Adequacy and appropriateness of geriatric-psychiatric units for persons with behavioral disorders associated with Alzheimer's and related dementia;
 - h. Assisted living residential options for persons with dementia; and
 - i. State support of Alzheimer's research through universities and other resources; and
3. Needed state policies or response, including, but not limited to directions for the provision of clear and coordinated services and supports to persons and families living with Alzheimer's and related disorders and strategies to address any identified gaps in services.

*Although the legislation refers to "Alzheimer's and developmental disabilities", the Task Force discussed the use of the phrase "developmental disabilities" at meetings and the Task Force requested that the phrase be removed from the legislation. Representative Joe Armstrong said he would amend the legislation. The phrase "and related dementia" was recommended.

Task Force Meetings

The formal work of the Task Force began on October 10, 2007. Organizational issues were addressed with Representative Joe Armstrong and Senator Rusty Crowe elected as Co-Chairs and Janice Wade-Whitehead elected as Secretary. The requirements of the legislation were reviewed, dates for Task Force reports were identified, and points for consideration were identified.

In addition, the Task Force, through special presentations, gained background information concerning the issues, needs, and resources. Presentations were provided by Kate Gordon from the National Alzheimer's Association who discussed the development of a State Plan, the use of work groups to achieve the goals of the Task Force, public forums, and other State Alzheimer's disease plans; Aaron Campbell, Department of Mental Health and Developmental Disabilities, who distributed the State Alzheimer Disease Roadmap as proposed by the Tennessee Alzheimer's Association with recommendations from the Tennessee Department of Mental Health and Developmental Disabilities and the Tennessee Department of Health; Patti Killingsworth, Assistant Commissioner and Chief of Long Term Care, Tennessee Department of Finance and Administration, who discussed home and community-based waivers, core services, point of entry, alternatives to nursing home care, and the Long Term Care Community Choices legislation; and Catherine D. Freiman, Ph.D., who provided information on the present and future of Alzheimer's disease in America.

Work Groups

Three (3) work groups were established utilizing the Revised State Alzheimer's Disease Task Force Roadmap (Appendix 2) and an informal identification of needs by the Task Force. The work groups were State of the State, Clinical Health Services, and Options for Long Term Care. Each work group was chaired by members of the Task Force who were charged with recruiting work group members to provide input and develop possible recommendations to present to the Task Force for review and approval.

Public Forums

Public forums were held throughout Tennessee in May and June at the following locations: Knoxville, Blountville, Chattanooga, Cookeville, Murfreesboro, and Memphis. Each forum was opened with specific questions developed by Task Force members to ensure some consistent data statewide and to identify regional issues. Attendees represented agencies and organizations that provide services; caregivers; family members; individuals with Alzheimer's and young onset Alzheimer's; medical profession; and others. Attendees provided personal experiences and recommendations on how to best serve persons with Alzheimer's and their family members. The forums were two hours in length and attendance ranged from 40 to 80 attendees per site.

In addition to some concerns that related specifically to the region, some of the common threads that ran through all of the public forums included: concerns about funding and resources; availability and condition of facilities; available professional and medical services; public awareness, training and education; appropriate diagnosis; medications; range and options for care; insurance and legal issues; transportation; ethnic and cultural issues; and communication among all parties involved in managing the disease (Appendix 3).

The focal concern expressed strongly at all of the forums was for persons with Alzheimer's, their caregivers, and their families. Alzheimer's is a family disease that devastates the family financially, emotionally, spirituality, and physically. All family members need help and support to survive. Quotes from attendees who spoke at the public forums are included in Appendix 4.

Alzheimer's Disease

Overview and Treatment

Alzheimer's disease is a progressive and fatal neurodegenerative disorder manifested by cognitive and memory deterioration, progressive impairment of activities of daily living, and a variety of neuropsychiatric symptoms and behavioral disturbances. Prevalence studies estimate the number of persons with Alzheimer's disease in the United States at 5.2 million. Every 71 seconds someone is diagnosed with Alzheimer's disease in the U.S. According to the 2000 U.S. Census an estimated 100,000 persons in Tennessee had Alzheimer's disease. The prevalence is expected to increase 20% by 2010. Without advances in therapy, the number of symptomatic cases in the United States is predicted to rise to 13.2 million by 2050. It is estimated that Alzheimer's disease will strike one out of eight baby boomers. Now is the time to address this looming epidemic that currently has no cure.

Alzheimer's disease is the most common form of dementia. Dementia is a general term for the loss of memory and other intellectual abilities severe enough to interfere with daily life. The classic clinical features of Alzheimer's disease are memory impairment, deterioration of language and problems with abstract thinking. Functional and behavioral disturbances are characteristic of the disease as well. Patients progress from the loss of higher-level activities, such as check writing and the use of public transportation, through abnormalities of basic activities of daily living such as eating, grooming and toiletry as the disease advances. Behavioral disturbances also progress over the course of the illness. Mood change and apathy commonly develop early and continue for the duration of the disease. Psychosis and agitation may also exist. Some causes of dementia are vascular dementia, dementia with Lewy Bodies, Parkinson's disease (many individuals with Parkinson's develop dementia in later stages of the disease) and Frontotemporal dementia.

While there is no cure for Alzheimer's disease, drug and non-drug treatments may help with both cognitive and behavioral symptoms. Researchers are looking for new treatments to alter the course of the disease and improve the quality of life for people with dementia. The U.S. Food and Drug Administration has approved two types of medications to treat cognitive symptoms of Alzheimer's disease. These drugs affect the activity of two different chemicals involved in carrying messages between the brain's nerve cells. The first type is cholinesterase inhibitor that prevents the breakdown of acetylcholine, a chemical messenger important for learning and memory. There are three cholinesterase inhibitors commonly prescribed for Alzheimer's: Aricept, Exelon and Razadyne. The drug Namenda uses a different approach. This drug works by regulating the activity of glutamate, a different messenger chemical involved in learning and memory.

For many individuals, Alzheimer's disease affects the way they feel and act in addition to impacting memory and other thought processes. As with cognitive symptoms, the chief underlying cause is progressive destruction of brain cells. In different stages of Alzheimer's, individuals may experience physical or verbal outbursts, general emotional distress, restlessness and sleep disturbances, wandering, hallucinations and delusions. Approaches used to manage

behavioral symptoms include using medications specifically designed to control the symptoms and non-drug strategies. Non-drug approaches should always be tried first.

While scientists know Alzheimer's disease involves progressive brain cell failure, they have not yet identified any single reason why cells fail. However, they have identified certain risk factors that increase the likelihood of developing Alzheimer's. According to the Alzheimer's Association, those risk factors include:

Age – The greatest known risk factor for Alzheimer's is increasing age. The likelihood of developing Alzheimer's doubles about every five years after age 65.

Family History – Research has shown that those who have a parent, brother or sister with Alzheimer's are more likely to develop the disease. It increases if more than one family member has the illness. When diseases tend to run in families, either heredity or environmental factors or both may play a role.

Head Injury – There appears to be a strong link between serious head injury and future risk of Alzheimer's.

The Heart / Brain Connection – Strong evidence links brain health to heart health. The risk of developing Alzheimer's or vascular dementia appears to be increased by many conditions that damage the heart or blood vessels. These conditions include high blood pressure, heart disease, stroke, diabetes and high cholesterol.

Exercise and Social Activity – Other lines of evidence suggest that strategies for overall healthy aging may help keep the brain healthy and may even offer some protection against developing Alzheimer's such as staying socially connected and exercising both body and mind.

Caregiving

Alzheimer's is a family disease. It captures and involves the whole family, physically, spiritually, emotionally, and financially. The whole family needs assistance. According to the ***2008 Alzheimer's Facts and Figures***, "almost 10 million Americans provide unpaid care for a person with Alzheimer's disease or another dementia. These unpaid caregivers are primarily family members, but also include friends and neighbors. About 60 percent of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters and other female relatives."

Caregiving impacts the emotional well-being, health, employment, income, and financial security of the caregiver. Caregivers demonstrate high levels of stress and depression. They experience negative health outcomes such as reduced immune function, slow wound healing, new hypertension and coronary heart disease. The caregiver may be required to quit work, reduce his/her hours, take time off frequently, and/or turn down promotions. The caregiver's income and financial security if the caregiver resigns and loses the job-related income and benefits that may include contributions to his/her retirement savings by the employer. Caregiving also results in related and out of pocket expenditures.

Law Enforcement and Dementia

Currently several law enforcement agencies across the State of Tennessee have developed or adopted programs and services for seniors. Some of the programs have application for the Alzheimer's community. Programs and services vary with the local entity – some examples of programs include:

SCAN (Senior Citizen Awareness Program) provides services to the elderly and disabled and helps relieve the uniformed patrol officers from performing these time consuming tasks. Six days a week, volunteers check on the safety and security of older citizens who have enrolled in the free program. Volunteers provide confirmation of personal well-being, crime prevention information, victim outreach, companionship, and conduct home security surveys.

Project Livesaver helps reduce the fear of family members who have adults or children in their homes with a tendency to wander due to Alzheimer's, dementia, Down Syndrome or Autism.

Safe Return Training is a program of the Alzheimer's Association. Safe Return MedicAlert is a 24-hour nationwide emergency response service for individuals with Alzheimer's who wander or who may have a medical emergency. The program has a law enforcement training component that is provided by the Alzheimer's Association. Some local law enforcement agencies utilize the training.

There are no uniform training programs on dementia for law enforcement agencies in the State of Tennessee.

Prevalence

Currently most of the information on prevalence is obtained from the *2008 Alzheimer's Fact and Figures*.

National

The number of persons with Alzheimer's disease is growing as the baby boomers age. Ten (10) million United States baby boomers will develop Alzheimer's disease. Every 71 seconds someone in America develops Alzheimer's disease. By mid-century, it is estimated to be 33 seconds. In 2008, as many as 5.2 million Americans of all ages are living with Alzheimer's. Alzheimer's is the sixth leading cause of death.

Tennessee

According to the *2008 Alzheimer's Facts and Figures*, Tennessee currently has 100,000 persons with Alzheimer's over the age of 65. That number is expected to increase to 120,000 by 2010, a 20% increase. Fifteen (15) out of the 50 states have rates of 20% and above. This increase may be the result of people choosing to age in place and people

retiring to Tennessee. Of those persons with Alzheimer's, 5-10% expressed symptoms prior to age 65.

Cost of Care

The direct and indirect costs of Alzheimer's and other dementias to Medicare, Medicaid and businesses amount to more than \$148 billion each year.

To the Family:

According to the *Genworth Financial 2008 Cost of Care Survey*, the cost of care to a Tennessee Family for a person with Alzheimer's through private pay is:

- \$15.79 hourly rate for home health aides in 2007 or \$36,128.00 for 44 hours per week for 52 weeks;
- \$12,004.00 annually for adult day services for 5 days a week;
- \$32,744.00 annually for a one bedroom assisted living residence;
- \$213.00 daily for a private room in a nursing home or \$58,139.00 for the year.

According to the data from the Tennessee Comptroller's office, the average Medicaid Level I rate has increased by 4.61% over the past five years. For FY 2008-2009, private pay rate is approximately \$153.00 or about \$55,845 annually.

Forty-nine percent (49%) of family and other unpaid caregivers of persons with Alzheimer's and related dementia (not including spousal caregivers) had caregiving-related out of pocket expenditures that averaged \$219 a month.

To Business:

According to the *Alzheimer's Disease: The Cost to United States Businesses in 2002*, the national cost to businesses of health care for people with Alzheimer's disease is \$24,634 billion. This represents more than one-third (36.52%) of the total cost of health care for people with Alzheimer's disease.

To the State of Tennessee (FY 2008-2009):

The cost of each service provided by the State is:

Home and Community based Services (HCBS)	\$ 10,127,900.00
HCBS Electronic visit Verification	\$ 933,400.00
HCBS Rate Equalization	\$ 944,000.00
(TennCare, Tennessee Commission on Aging and Disability)	
Nursing Home Services (Long Term Care)	\$330,000,000.00
	(without federal match)
	\$940,000,000.00
	(with federal dollars)

To the Caregivers:

According to the *2008 Alzheimer's Facts and Figures*, the hours of unpaid care and the economic value of the care in 2007 for 222,830 caregivers who provided 192,346,581 hours of care was \$2,035,026,828.00.

- Sixty percent (60%) of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters and other female relatives, friends and neighbors.
- Among the caregivers, 18 years of age and older, 19% were under the age of 35; 29% were 35-49; 37% were ages 49-64; and 14% were age 65 and over. Their average age was 48.
- Fifty-seven percent (57%) of caregivers were employed full time or part time.
- Of those who were employed, two-thirds said they had to go in late, leave early, or take time off because of caregiving; 18% had to take a leave of absence; 13% had to reduce their hours; 8% turned down promotions; and 8% had to quit work entirely because of caregiving.
- Caregivers of persons with Alzheimer's and other dementias with behavioral symptoms were 68% more likely to reduce their hours or quit work.

Data on Facilities and Services in Tennessee

Telephone Survey of Nursing Facilities

Task Force member Jeff Beaty and his staff conducted a telephone survey during October 2008. Two hundred and eight-four (284) nursing facilities were contacted. Data from two questions have been compiled for this overview:

1. Special Care Unit? If yes, Closed Unit or Alzheimer's Distinct Unit?

54 (19%) of the nursing facilities responded, "Yes" and included some of the following responses:

- Locked Behavior Unit
- SNF Unit only
- Alzheimer Unit State Certification
- Closed Behavior Unit
- Advanced Alzheimer Unit
- Behavior Unit
- Locked State Certification
- Memory Support Alzheimer's
- Dementia Unit
- Dementia Unit – No State Certification
- Secure Behavior Unit
- Closed Unit, Not Certified
- Secure Unit
- Dementia/Alzheimer Unit

2. Quality Care Improvement/Measurement: Dementia Training? Y or N; How much? How often?

Quality Care Improvement/Measurement: Dementia Training?

- 214 (75.4%) of the nursing facilities responded “Yes”
- 55 (19.4%) of the nursing facilities responded “No”
- 6 (2.1%) of the nursing facilities responded “Uncertain”
- 9 (3.1%) of the nursing homes did not provide data for this question

Quality Care Improvement/Measurement: How Much?

- Of the 214 nursing facilities, data for this question were available for 105 facilities.
- “In-service” was the primary response to this question; however, other responses included the following: 8 hours, 10 hours, 40 hours, sporadic, orientation, seminars, 2-3 times a year, new hires/pre-employment.

Quality Care Improvement/Measurement: How Often?

- Data were available for 214 nursing facilities.
- “Annually” was the primary response to this question; however, other responses included the following: 40 hours, in-service, quarterly, frequently, continuous, seminars, orientation, monthly, 1-2 times a year, bi-annually, new hires, uncertain, off-site, in-service on a regular basis, clinical.

Other responses to the training question included certain employees, required training before you can work on unit, not routine, working on program for techs, based on need, NSG Rehab.

Information from this survey is also available for ICF, SNF or Dual Certification, Cost, and Quality Care Improvement/Measurement: Physical Planning and Access.

Data from the Tennessee Department of Health Joint Annual Report of Nursing Homes 2006

Data was available for a total of 334 nursing home facilities. The data were compiled from **Schedule D – Facilities and Services – Part 1**. The report did not include information on the training of the staff. The services identified for inclusion in this report are:

- Continuing Care Retirement Community (Independent Apartment Living, Assisted Care Living and Home for the Aged);
- Adult Day Services (Adult Day Services has minimal medical and social supervision for the older person who has help at home during the evening, but whose family or spouse is employed during the day. Services can include general assistance with the needs of daily living, socialization and lunches. In some instances, restorative and therapeutic programs may be included.);
- Respite Care Services (Respite care is when the resident’s care program involves a short-term stay in the facility for the purpose of providing relief to a nursing facility-eligible

Section 1: Infrastructure

In order to provide a coordinated and comprehensive system of services and programs to persons with Alzheimer's disease and related dementia and to their families, an underlying organizational framework must be in place to support the system of services and programs. The organization must have a structure that allows for the opportunity and the flexibility to facilitate the effective delivery of services and programs; to partner with other organizations that provide services to the identified population; to communicate effectively with all of the partners who provide support both to the organization and the identified population; to develop and/or support policies, procedures, and guidelines that address the needs and conditions of the identified population; to provide current and accurate information on Alzheimer's disease and related dementia; and to collect and analyze data for decision-making regarding the services and programs offered to the identified population. The following recommendations have been developed to address an effective infrastructure.

- I. Recommendation:** Develop a comprehensive infrastructure for Alzheimer's disease and related dementia (ADARD) through the Tennessee Commission on Aging and Disability (TCAD).

Action Steps:

1. Meet annually as specified in Public Chapter 566, Section 7, "The Tennessee Alzheimer's Disease Task Force (TADTF) shall meet after the state plan is submitted at least annually to review the need for new components to the state plan."
2. Develop a plan to transition the Tennessee Alzheimer's Disease Task Force (which sunsets in one year) to the Alzheimer's Advisory Committee under the Tennessee Commission on Aging and Disability to:
 - oversee the development of strategies to implement the recommendations of the Tennessee Alzheimer's Disease Task Force
 - oversee the State Plan for Alzheimer's and revise as necessary to meet the changing needs of persons with Alzheimer's disease and related dementia
 - report to the Commission at least annually and quarterly, if needed
 - select Committee members from experts in the field of Alzheimer's disease and related dementia and from the community
3. Ensure that all recommendations coalesce with other initiatives and programs within the State.
4. Develop a comprehensive communication plan to ensure ongoing planning and discussion among stakeholders for coordination of services and ensure that the stakeholders receive the most current and accurate information regarding Alzheimer's disease and related dementia:
 - Partner with the Alzheimer's Association (AA), Area Agencies on Aging and Disability (AAAD), Tennessee Department of Health (TDOH), Tennessee Department of Mental Health and Developmental Disabilities

- (TDMHDD), Tennessee Hospital Association (THA), Tennessee Medical Association (TMA), AARP, Tennessee Respite Coalition (TRC), Adult Protective Services (APS), Tennessee Health Care Association (THCA), Tennessee Association of Adult Day Services (TAADS), Tennessee Association of Homes and Services for the Aged (TNAHSA), Tennessee Association of Home Care (TAHC) and all other relevant entities
- Education the general public about the important of early diagnosis and treatment, how participation in healthy aging/lifestyle choices can prevent or delay the disease, the importance of maintaining good health care, and how to make financial and legal decisions
 - Furnish legislators, the public and news media information pertaining to the latest developments and services in the field of Alzheimer's disease and related dementia
 - Coordinate efforts to assure the flow of information among separate service providers, government agencies and appropriate authorities
 - Ensure that all persons with dementia and their caregivers are informed of any research projects and therapeutic trials open for their participation
 - Fund public awareness efforts and educational efforts for providers, caregivers, and State oversight and monitoring personnel
 - Keep Tennesseans healthier and reduce the risk for developing Alzheimer's disease and related dementia
 - Use technology to provide support to caregivers across the state, e.g. telephone support lines, on-line chats, web cam support, teleconference and videoconference support groups, etc.
5. Use technology and marketing strategies to connect individuals and family to services that are available in their community including services provided from private and public sectors
 6. Increase public awareness and outreach concerning Alzheimer's disease and related dementia and the available services and service providers in Tennessee
 - Information dissemination services, including the causes, symptoms, brain health and early detection, lifestyle changes, and successful aging
 - Tennessee Department of Health could take Alzheimer's awareness on as new campaign
 - "One stop shop" for referrals such as the Aging and Disability Resource Connection (ADRC) that has begun to build a database of "elder friendly" physicians
 - Alzheimer's Association/Tennessee Department of Health/Area Agency on Aging and Disability (AAAD) could partner to look for dementia-specific grants to cover costs of some proposals
 - Join together or add to existing campaigns through the Tennessee Department of Health to promote the Alzheimer's Association's "Maintain Your Brain"

7. Partner with Alzheimer's Associations and Area Agencies on Aging and Disability to identify current resources and data and to market contact information
8. Partner with the Tennessee Department of Finance and Administration, State Health Planning, to ensure that accurate and up-to-date information on Alzheimer's disease and related dementia is included in the Tennessee Health Plan.

II: Recommendation: Improve access to adult day programs, respite and homemaker services, assisted living, transportation and other community-based services

Action Steps:

1. Disseminate information on services and related activities for persons with Alzheimer's disease and related dementia to the medical and healthcare community, academic community, primary family caregivers, advocacy associations and the general public
2. Establish a strategy to link and coordinate services and activities of State agencies, other service providers, advocacy groups, and other entities throughout the State such as emergency personnel, police, universities and attorneys and other staff associated with the legal system
3. Encourage non-governmental resources, including clergy, faith-based organization, civic groups, and other volunteers to provide services for dementia patients and their families
4. Utilize the stakeholder community to revise the current definition, eligibility and service requirements for the provision of respite

III. Recommendation: Provide access to affordable transportation options in all areas of Tennessee, urban and rural

Action Steps:

1. Determine the specific transportation needs of persons with dementia
2. Examine transportation options currently available to persons with dementia
3. Partner with Tennessee Department of Transportation on a plan to provide transportation options to get individuals to services

IV. Recommendation: Develop driving guidelines for persons with dementia

Action Steps:

1. Partner with the Older Drivers Safety Coalition coordinated by the Tennessee Department of Transportation to provide input and resources

- V. Recommendation:** Enhance and strengthen the infrastructure to provide a continuum of care for persons with Alzheimer's disease and related dementia and their caregivers to address the progression of the disease from mild to severe and to allow flexibility to move within the care system depending on the needs of the persons with Alzheimer's disease and related dementia and their families

Action Steps:

1. Provide case managers to help navigate the system
2. Include, but not be limited to, the following in the continuum of care:
 - information dissemination services;
 - diagnostic services, specialists such as geriatricians, geriatric psychiatrists and nurses;
 - legal services, public guardian services, and adult protective services that provides more than referrals;
 - support services including day programs, home care, and financial assistance programs;
 - hospital based services including geriatric units (medical and psychiatric), and geriatric care teams;
 - family services, including education, social services, and psychology/psychiatric care;
 - assisted living including special programs, secured dementia units with outdoor space and programming
 - nursing homes including dementia units, hospice, and restraint free care models; and
 - a program for all-inclusive care for the elderly.

- VI. Recommendation:** Encourage awareness of elder care law and access to attorneys with training in elder care law

Action Steps:

1. Partner with attorneys in private practice to increase their awareness of issues related to Alzheimer's disease and related dementia
2. Partner with the Legal Assistance Program in Area Agency districts funded by the Tennessee Commission on Aging and Disability to provide training to attorneys on elder care law
3. Encourage attorneys to obtain continuing education on elder care law and encourage law schools to include a module of elder care law in the curriculum

Section 2: Data

In order to accurately assess the current and future impact of Alzheimer's disease and related dementia on Tennesseans and the systems that deal with the impact of the disease, Tennessee needs a comprehensive and coordinated data collection system. Although the current system does provide some limited data, it is piecemeal and does not provide enough data information on which to base decisions addressing Alzheimer's disease and related dementia. To achieve the most appropriate and accurate data collection system for Tennessee, the following recommendation is being made:

- I. Recommendation:** Establish an effective coordinated and comprehensive surveillance system or enhance the current surveillance and epidemiology system to include Alzheimer's disease and related dementia.

Action Steps:

1. Partner with the Tennessee Alzheimer's Association, Tennessee Department of Health, Tennessee Department of Mental Health and Developmental Disabilities, Tennessee Commission on Aging and Disability, and all other relevant agencies and organizations to design and implement a data system that is consistent statewide and to ensure that the data are analyzed and reported to support and guide decisions regarding Alzheimer's disease and related dementia
2. Partner with the Tennessee Department of Health, Office of Health Statistics to determine if the existing system can collect the requested data
3. Request the addition of questions related to Alzheimer's disease and related dementia on the Behavioral Risk Factor Surveillance System (BRFSS) that will produce state information on 1) the number of people with Alzheimer's disease and related dementia, 2) the number of family caregivers who are taking care of someone with Alzheimer's disease and related dementia, and 3) the age, income, living arrangements, health problems and other characteristics of people with dementia and their family caregivers
4. Collect data from existing sources, monitor at a minimum the following data sets, and make the data available at the Tennessee Commission on Aging and Disability:
 - The prevalence of dementia related diseases across the State
 - The prevalence of dementia related diseases by county
 - The prevalence of young onset dementia related diseases across Tennessee
 - The prevalence of inpatient geriatric psychiatric beds
 - The use of antipsychotic medications and restraints for Alzheimer's disease and related dementia behaviors
 - The availability of geriatric services and specialists
 - The availability of dementia related services and supports

- The availability of assessment services for Alzheimer's disease and related dementia
- The number and location by county of Tennesseans who are currently providing care in their homes to a family member
- The number and location by county of Tennesseans who are currently receiving care through: adult day programs, assisted living programs, home for the aged programs, group homes programs, Medicaid waiver services, non-medical companion programs, and homemaker programs

Section 3: Education and Training

To address the growing number of individuals with Alzheimer's disease and related dementia and their needs will require a very prepared workforce. Individuals who attended the public forums expressed the need for education and training for caregivers, family members, health professionals, hospital staff, primary care physicians, law enforcement, adult day services, nursing homes and assisted living staff, Adult Protective Services, and others working with persons with Alzheimer's disease and related dementia. Some of the topics suggested included stages of Alzheimer's disease, associated needs and appropriate treatment, memory loss, handling different and difficult situations, stress management, activities for people with Alzheimer's disease, nutrition, and up-to-date information. In addition, more public awareness is needed as the "baby boomers" age and the number of persons with Alzheimer's disease and related dementia grows. According to the responses from the public forums, Alzheimer's disease and related dementia should get the same recognition as breast cancer. To address the issues of education and training, the following recommendations are being made:

- I. Recommendation:** Educate physicians and other health care professionals to improve accurate diagnosis and appropriate treatment and referrals as early in the disease process as possible

Action Steps:

1. Provide training, consultation and continuing education to the public, students, surveyors, residents, practicing physicians and other health care professionals, thereby enhancing the standard of care in Tennessee
2. Work with the universities to develop specific training and recruitment options including:
 - develop optimal training content standards for licensed health professionals in their educational curricula
 - develop an incentive program to recruit and train geriatricians, geriatric psychiatrists, and other geriatric specialists
 - develop a specific track on Alzheimer's disease and related dementia for medical students at state medical schools
3. Identify and partner with health care associations that offer educational courses in the area of Alzheimer's disease and related dementia to provide accurate and appropriate training

- II. Recommendation:** Strengthen training in geriatrics, especially dementia training, for all health professionals including physicians, nurses, other allied professionals and other members of the medical community

Action Steps:

1. Explore and identify the correct vehicles for providing training to the appropriate professional disciplines within the medical community

2. Provide training to all physicians and nurses in training through the addition of programs specifically on Alzheimer's disease and related dementia to be included in the residency and nursing curricula
3. Encourage physician organizations to provide Continuing Medical Education (CME) on Alzheimer's disease and related dementia for members in their area of specialty
4. Train primary care physicians to recognize young onset dementia, to screen for dementia earlier, and to appropriately utilize community support services
5. Explore the use of a geriatrician "mentor" in appropriate areas
6. Expand specialty training and training for general practitioners
7. Provide more programs in gerontology
8. Provide loan forgiveness programs for physicians going into geriatrics similar to "loan forgiveness" act for nurse practitioners in Tennessee
9. Examine "loan forgiveness" programs in North and South Carolina for physicians willing to go into geriatrics
10. Examine the possibility of providing extra benefits to physicians practicing in rural areas with documented additional training and qualifications in geriatrics
11. Reduce rates for certification for professionals in the field
12. Partner with the Tennessee Medical Association (TMA) and the Tennessee Hospital Association (THA) to formulate requirements and advocate with The Joint Commission to require showing competencies in dementia-specific care
13. Address early diagnosis of Alzheimer's disease by implementing screening and diagnostic services such as appropriate cognitive tests or diagnostic laboratory and/or imaging through the current medical system for any patient whose family member indicates a concern

III. Recommendation: Establish or enhance policies, procedures and incentives to incorporate evidence-based practices into training, service and program activities

Action Steps:

1. Explore current policies, procedures, and incentives concerning evidence-based practices, if available

2. Compile a list of evidence-based practices that might be appropriate for implementation in Tennessee

IV. Recommendation: Increase and enhance training on Alzheimer's disease and related dementia for various stakeholders

Action Steps:

1. Identify specific training resources for targeted audiences across the state. Utilize existing resources and materials and develop partnerships with universities, medical schools, community colleges, senior centers and other interested organizations such as the Alzheimer's Association
2. Develop a plan to broaden the spectrum of people who receive Alzheimer's disease and related dementia training:
 - Identify those individuals, agencies, organizations and facilities that need training, but do not currently receive the training
 - Work with the identified entities to develop appropriate training modules
 - Develop a time line for implementation of the training
3. Partner with law enforcement and their community partners to develop and implement ongoing in-service training on Alzheimer's disease and related dementia through programs such as Safe Return
4. Develop and implement evidence-based training curriculum and implementation strategy for targeted audiences such as the Tennessee Department of Mental Health and Developmental Disabilities, Nursing Home surveyors, and Long Term Care facilities
5. Partner with emergency personnel to include Alzheimer's disease and related dementia training as part of yearly in-service program
6. Partner with Tennessee Hospital Association and emergency room staff to design and implement dementia-specific training appropriate to all personnel involved in providing emergency services, such as physicians, nurses, and related service technicians
7. Increase training for state adult protective services workers on Alzheimer's disease and related dementia
8. Provide Alzheimer's disease and related dementia training for providers and state staff associated with the Medicaid home and community-based waiver
9. Develop a portable certification program for paid and unpaid direct caregivers with standardized content designed to enhance their understanding of memory

impairment and their performance in care for those with Alzheimer's disease and related dementia

10. Establish Quality Care measures with system benchmarks for facility and community based care for persons with Alzheimer's disease and related dementia, such as the Alzheimer's Association "Standards of Care"
11. Convene a workgroup on a regular basis to address psychological-geriatric needs of persons with dementia (PWD) in Tennessee

- V. **Recommendation:** Educate caregivers through the Alzheimer's Association and other agencies, provide support, and possible referral to mental health services, paying attention to caregiver's mental state during office visits

Action Steps:

1. See Websites listed in Appendix 6.

Section 4: Services and Facilities

In order to make appropriate recommendations concerning improved health outcomes, the Task Force looked at the entire system of care. To improve the quality of life and health for person with Alzheimer's disease and related dementia, services and programs provided by agencies, organizations, and facilities should address the current unmet needs of persons and their families impacted by Alzheimer's disease and related dementia as well as future needs. Alzheimer's is a progressive disease that will ultimately result in death; however, appropriate services at the appropriate stage can delay the progression and improve the quality of life. Young onset of the disease must also be addressed.

Attendees at the public forums identified the need for more support groups, respite care, more resources, and day care programs; however, a sampling of other needs identified include the following: a continuum of facilities including intermediate services; services in rural areas; a single point of entry or "one stop" agency for services and information; a wide range of options for care across the entire spectrum of the disease; more home and community-based care and services; coordination among services; individual care plans; care management and/or care coordination; consistent regulations and licensure for services and facilities; spectrum of care since it is a long lasting disease and the flexibility to move within the system; focus on caregivers as well as the persons with Alzheimer's disease and related dementia; facilities for persons with Alzheimer's disease and related dementia with other physical and/or behavioral problems; and small group homes. The following recommendations are being made to address the identified issues.

- I. Recommendation:** Develop a multi-disciplinary approach in partnership with the Tennessee Hospital Association, Tennessee Medical Association, and all other relevant entities to address Alzheimer's disease and related dementia in the hospital setting to enhance the well-being and safety of the individual

Action Steps:

1. Develop a system for Alzheimer's disease and related dementia patients similar to "falls" bracelet system in current use, to alert staff to the risks associated with Alzheimer's disease and related dementia and provide staff training
2. Identify patient's true needs at point of discharge (sometimes dementia isn't primary concern), assess the caregiver's abilities/limitations (sometimes nursing facilities are the only option given to family members); involve the family and their needs in planning; and develop a special check-list/survey for persons with dementia (PWD)
3. Partner with the Tennessee Hospital Association and the Tennessee Medical Association to develop protocol for emergency care of persons with dementia that could include:
 - Identification of the underlying precipitating factors of the altered mental status at the time of admission
 - distinguishing, if possible, whether it is dementia or delirium

- ensuring that personnel have the knowledge and training to manage agitated patients
4. Partner with the Tennessee Hospital Association to provide a “point person” at each hospital responsible for coordinating support for the person with dementia and his/her family
 5. Partner with Tennessee Hospital Association and the Tennessee Medical Association to require physicians who provide geriatric-psych services to document additional training in geriatric-psych
 6. Provide a continuum of care for geriatric-psych patients who require both inpatient and outpatient care
 7. Explore minimum guidelines and strategies for improving communication and building stronger relationships between inpatient and outpatient providers

II. Recommendation: Partner with the Tennessee Department of Health and the Division of Health Care Facilities to review current dementia related regulations such as the full disclosure regulation and how the regulations are being implemented and enforced

Action Steps:

1. Partner with the Tennessee Board for Licensing Health Care Facilities to review the regulations as they are currently implemented and to develop recommendations for additional requirements, if needed
2. Partner with the Tennessee Department of Health to ensure that providers (nursing homes, assisted care living facilities, home health agencies) as well as surveyors have updated and current information on Alzheimer’s disease and related dementia in order to more accurately evaluate a facility accepting and caring for patients with Alzheimer’s disease and related dementia

III. Recommendation: Increase and improve support, counseling and education for family and informal caregivers to provide information on available support services and the importance of maintaining their own health

Action Steps:

1. Examine the feasibility of providing more day services through the Options for Community Living program based on a sliding fee scale
2. Provide an efficient method of identifying and tracking resources across the Tennessee
3. Examine linkages with existing options, such as the National Family Caregiver Program, inpatient respite care and the Alzheimer’s Innovation Grant

- IV. Recommendation:** Encourage the State to explore alternative programs of care, especially for elderly with dementia

Action Steps:

1. Examine successful regional programs currently available such as the Program of All-Inclusive Care for the Elderly (PACE) program in Chattanooga
2. Examine innovative programs currently being implemented in other states, such as group homes in Arizona and pods for Alzheimer's external to the facility in Oregon

- V. Recommendation:** Provide support and assistance to the rapidly increasing numbers of Tennesseans and their families with Alzheimer's disease and related dementia who are above the poverty level by providing a wide array of home and community based services based on a sliding fee scale

- VI. Recommendation:** Provide access to basic clinical evaluation(s) including help for families and informal caregivers, in relation to ongoing case management

Action Steps:

1. Provide diagnostic services, treatment and case management to patients and families throughout Tennessee, especially to rural areas of Tennessee
2. Access to optimal care for more Tennesseans in all parts of the state
3. Modify existing community needs assessment process to include questions that would identify and quantify at-risk persons with dementia (PWD), including those under 65

Section 5: Health Coverage and Funding

Obtaining funding to address the needs of a growing population with Alzheimer's disease and related dementia will require careful planning and creative thinking. Attendees at the public forums had the following comments regarding financing a solution that would lessen the impact of the disease: Medicaid will not pay for bed alarms that prevent injury, but will pay for care for the injury; paying for care is a problem for those above the poverty level since the expense often depletes the family's income and savings; reimbursement issues; advocating for a change in asset limits; and more State funded options for assistance. The following recommendations are being made.

- I. Recommendation:** Ensure access to affordable health coverage for Alzheimer's disease and related dementia, and mental health issues from the private sector and those not eligible for government funding

Action Steps:

1. Provide another level of disease management coverage by increasing the time that home health can assist persons with Alzheimer's and related dementia and extend time for non-skilled care
2. Examine how health coverage for persons with dementia or caregivers could transcend to other persons that may not be covered
 - include persons other than spouse
 - meet stipulations such as same address, direct caregiver responsibility
3. Examine the possibility of ongoing health coverage for caregivers who have to quit their employment for caregiving purposes

- II. Recommendation:** Provide options to increase insurance coverage for persons with Alzheimer's disease and related dementia

Action Steps:

1. Explore changes needed to ensure Medicaid eligibility for young onset dementia
2. Explore services and options available under private insurance entities
3. Provide more tax incentives for individuals who purchase long term care insurance
4. Provide educational resources to the public for better understanding of long term care financing

- III. Recommendation:** Develop a plan for providing funding to individuals and/or facilities that are engaged in research on Alzheimer's disease and related dementia

- IV. Recommendation:** Ensure that Adult Protective Services and Guardianship services are adequately funded to meet the needs of vulnerable adults

Action Steps:

1. Partner with the Tennessee Health Care Association and the Tennessee Hospital Association to develop a plan to secure an emergency placement system for cognitively impaired adults in dangerous situations and to ensure that providers receive appropriate funding for caring for vulnerable adults that are placed in the facilities by the Adult Protective Services
2. Support the Tennessee Department of Human Services in providing Adult Protective Services to persons with Alzheimer's disease and related dementia
3. Support the Silver Alert rapid response program to locate at risk persons with cognitive loss

APPENDIX 1

PUBLIC CHAPTER NO. 566

SENATE BILL NO. 826

**By Burchett, Henry, Raymond Finney, McNally, Burks, Mr. Speaker
Ramsey, Crowe, Woodson, Southerland, Jackson, Ketron, Tracy, Black,
Bunch, Harper, Marrero, Kilby, Haynes, Herron, Wilder, Beavers, Cooper,
Crutchfield, Lowe Finney, Ford, Johnson, Kurita, Kyle, Norris, Stanley,
Tate, Watson, Williams**

Substituted for: House Bill No. 1971

**By Armstrong, Eldridge, Pruitt, Favors, Jim Cobb, Odom, Hensley, Crider,
DuBois, Williams, Overbey, Shepard, Gresham, Mike Turner, Ferguson,
Sherry Jones, John Deberry, Harrison, Maggart, Tindell, Sontany,
Hackworth, Harry Brooks, Brown, Roach, Litz, Lundberg, Niceley, Ford, Hill,
Mumpower, McCormick, Fraley, McDaniel, Curt Cobb, Strader, Dunn,
McCord, Miller, Hawk, Swafford, Curtiss, Baird, Montgomery, Winningham,
Sargent, Harwell, Bass, Vaughn, Hardaway, Kevin Brooks, Yokley,
Coleman, Moore, Fitzhugh, Borchert, Hood, Fincher, McManus, Tidwell,
Pitts, Todd, Gilmore, Buck, West, Floyd, Coley, Lollar, Dean, Cooper, Curtis
Johnson, Bone, Bibb, Bell, Maddox, Towns, Matheny, McDonald, Rinks,
Briley**

**AN ACT to amend Tennessee Code Annotated, Title 4; Title 33; Title 68 and Title
71, relative to Alzheimer's disease.**

**BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF
TENNESSEE:**

SECTION 1. (a) The Tennessee Alzheimer's Disease Task Force (TADTF) is established. The TADTF shall consist of fourteen (14) volunteer members, who shall include the chairs of the Senate General Welfare Committee and the House Health and Human Resources Committee or their designees, one member of the Senate to be appointed by the Speaker of the Senate, one member of the House of Representatives to be appointed by the Speaker of the House of Representatives, at least one person with Alzheimer's disease, one caregiver of a person with Alzheimer's disease, a representative of the Tennessee Health Care Association, a representative of the Tennessee Association of Homes and Services for the Aging, a representative of the Tennessee Association for Adult Day Services, a representative of the medical care provider community, an Alzheimer's disease researcher, a representative of the Mid-South chapter of the Alzheimer's Association, a representative of the Eastern Tennessee chapter of the Alzheimer's Association, and a representative of the Northeast/Southeast Tennessee chapter of the Alzheimer's Association. Non-legislative members of the Task Force shall be appointed by the governor.

**Comments from the Tennessee Alzheimer's Disease Task Force Public Forum
June 5, 2008
Blountville, Tennessee**

*My mother and most Alzheimer's patients I know had to be encouraged to seek initial diagnosis by family. So community-based outreach education and civic organizations, senior citizen centers, schools, by doctors, nurses and trained Alzheimer's support workers such as the local chapter of Alzheimer's Association is critical to encourage early diagnosis and care . . . the best placement of diagnostic tools, programs and education should be a family physician, rural health care and at a primary care medical office.

tried using sitters in [my mother's] home. Mom quickly began to feel isolated. So we tried a day care program at a local assisted living center. Mom really enjoyed the socializations,

Mom's positive day care experiences made it easy to adapt Mom to assisted living facilities, residential programs.

Access to support groups and trained allied health professionals and trained volunteers is critical for families during the early stages and really throughout the entire course of the disease.

staff members in acute care facilities often don't seem to have the time to overcome communications with [dementia] patients and may not have time to interview caregivers and family members to fully assess symptoms or non-dementia illness in [dementia] patients.

primary concern is that all middle aged and younger adults with acute illnesses lack long-term care insurance for the most part and inadequate resources for early retirement.

*no real avenue for medications to be done correctly. . . . Home health will come out and do a teaching. But if you teach somebody who can't remember, what good does that do? A lot of people have moved across state, across country. We take care of a lot of people that hadn't even had children.

*things that need to be done, better identification, better resources . . . patients that make too much money to get on Medicaid waiver that cannot afford a private company There's nothing [to] do for them except wait for them to get worse and then it costs more money to put them in a nursing home,

Medicare won't pay for any of the services for medical equipment like Metalarms to allow someone to know when they're getting up and wandering. But yet, when that person breaks their hip, Medicare will pay to put them in the hospital and have surgery on the hip. If that doesn't make financial sense, I don't what does.

it's best if we can keep a patient at home. They thrive. They do better. They do better in their own environment. They eat better. They sleep better. There's only so many things that caregivers can do. They need the support. They do need learning respite.

family education is a big thing. Primary care physician is a big issue. If we can educate our primary care physicians, give them the support staff . . . to help diagnose and deal with these family issues

*basically what happens is most people by the time they get to [help], there's a major progression of the disease. And we're looking at behavioral issues then. Family are wore out. The patient is wore out. . . . my challenge . . . is why not add . . . screening for anyone who is 50 years of age or older – that could be a baseline.

need to look at the person as a holistic human being.

wish we had some type of centralized information area that if nothing else, that when you go to your primary care doctor, they could just give you a number and say call this number - that doesn't take a lot of time.

funding so that we can have adult day cares and respite cares for our consumers, . . . that we give ourselves as caregivers permission to take care of ourselves. Okay? . . . you cannot take care of a family member if you basically kill yourself doing it and have resources available and having treatment situations where you can treat not only the consumer but have the family as part of the treatment team,

e-mailing has been a wonderful resource for my family members that are out of town and across country.

*daughter of Sam Crump who passed away . . . the day before my birthday and three hours before [his son arrived], after six weeks in hands of the medical community, who he had entrusted for help and assistance with his memory loss and dementia issues. . . . I am sharing Sam's story in hopes that no one, not you or a loved one, is ever subjected to the same injustice and gross incompetence. He was over dosed. After three weeks [in a medical facility], the family asked one too many questions, and we were given less than 48 hours to find the next medical facility. My father's patient plan of care was drugs, toxic dangerous drugs, drugs that accelerated death. His death certificate reads cause of death, cardiac arrest. My father did not die of a heart attack. He died from toxins in his body, causing the shutdown of his vital organs, induced by the medical care therapists he entrusted and looked to for assistance.

what is needed in our region. Competent medical personnel who are trained and skilled in the areas of dementia and Alzheimer's disease, communication between previous medical doctors on the health of patients before treating, Alzheimer's patient care facilities, staffed by compassionate skilled professionals specializing in dementia and Alzheimer's patient care, low patient and skilled staff ratio, availability of neurologists and specialists, open and honest communication between families and the caregivers, family training to assist primary caregivers with techniques and strategies, working with patients on daily basis at home, availability of local reliable resources for families to contact for assistance with health care, education not only about the disease, but ways to make the patients' lives more enjoyable, dignified for as long as they can. Do not disregard the families of these patients. No one knows them better. My father's death was caused by ignorance, apathy and gross incompetence.

*every family should have a right. No rights shall be taken away, regardless of physicians, hospitals, whoever. They always should be given the opportunity to do what they want.

Does adult day care work? Does in-home and all that work? Yes, people don't realize is that people need a place to feel like they're still part of life and dignity and they have respect. And in doing that, they're able to socialize.

there is a racial issue with Alzheimer's, meaning they're not - when I say racial, not racial as problems but the race issue. Black - we're trying to now get our black people to understand Alzheimer's. We're educating our doctors. We're educating our families. We're trying to show them or allow them to understand that in doing the care, family members can no longer do the care by themselves. But they need to know what's out there, what's available and how they can get help.

*we need to do more to educate the community about services that are available, and we need to do that early on when there's not a problem. The Area Agency on Aging and Disability is the best kept secret.

*more encouragement and incentive for more mental status exams, making it beneficial to the primary care physician to do it may be the closest adult day center t them doesn't offer transportation. . . . physician home visits or nurse practitioner visits.

*why are we not following the VA model and have a centralized database of medication so that any doctor can g in and see what that person's been taking . . . for the last five or six years

* more needs to be done to give people information about services

*But it's hard to know where to start. It's hard to know what exactly [is] available. . . . you talk about contact measures. I didn't have a clue as to what contact measures was until I got my job as the church secretary. And to I needed to know about contact measures. . . . Make it simple for us that don't know where to start.

*there's an organization called Senior Navigator. It is a web site. They are becoming nationwide. T started in Virginia, and it does all senior service. The other thing I'd just like to mention is Community Mental Health is a great place to start.

*I think it's really important that we become more aware of what's available in Tennessee. We are the last state that provides home community based services for those who have spent down their resources. What we need for Alzheimer's patients, we need to have flexibility, that it's a progressive disease, that you start out at one level and then can move to another. And sometimes those moves can be put off for a while if you receive the right services . . . at the lower level and at the special home and community-based services.

everybody has different needs. They might have legal needs. They have medical needs such as medicine control. And they might have financial needs. . . and east access, single point of entry where . . . we advertise the fact and not keep it the best kept secret in the aging community.

*great lack of knowledge by health care providers on how to treat Alzheimer's and Alzheimer's patients. . . . does the general public know signs and symptoms? Some do, some don't. So what do we need to do to improve that? What else do we need? What are we missing? Caregivers specializing in geriatrics and dementia related illnesses. Why do we not have that? Probably because it's something that's not covered by insurance. What else is missing? Family caregiver education.

*[patient] would go to the primary care physician, it was almost as though his primary care physician was afraid to say the A word. He would just kind of go around to other avenues, other things he would say. And then one day, he [patient] was prescribed Aeroset.

without that day attending that seminar or class or whatever it was, we would have been truly, truly lost. But she [nurse who specializes in Alzheimer's patients] gave so much in one day that it was unreal, that helped us to know what might be coming next.

getting our primary care physicians informed and our nurses, our practitioners, our CNAs, everything, to get them really, really educated.

*a lot of the caregivers in need don't have access to the internet or are not used to using the Internet for those resources, so it's kind of a moot point when you say, hey, you can go to this website, and nobody goes to it.

*There is some kind of statistic that there's less interest of doctors coming into the geriatric field. So how are we going to address that when the baby boomers come up and we need more people to turn to for diagnoses and treatment?

*issue of insurance coverage with in-home care, nursing homes, assisted living, daycare programs. You know, it's not available as we would like it to be.

*hotlines for people who live alone because, unfortunately, not all of us have the loving families and access to care, and some people with Alzheimer's disease and dementia live by themselves as scary as that sounds.

*family doctor sometimes being more the problem instead of the solution, and basically, that they're not listening; listening versus hearing, as far as going into the doctor's office. need more education on this disease and how to treat it and how it needs to be diagnosed.

*more money for respite care because that's really what the caregiver needs. The caregiver needs respite, and respite costs money.

*Insurance companies to wake up and realize that respite should probably be a part of insurance. Insurance should be more affordable so that some of these folks who can't afford maybe long-term care policies will still have some type of access to respite throughout their journey.

*maybe one-stop shop

*more legal education on the part of the caregiver, and understanding what durable power of attorney means.

*just not knowing where to go for services.

*getting help for people living away in rural areas . . . rural areas have local libraries and maybe that would be a place to house a lot of information about this disease

*ethnic and cultural differences, . . . a lot of cultures don't necessarily seek out help because they feel like it's their priority to take care of it on their own.

*major gap in our community resources for Alzheimer's residents - and that's for that subset of Alzheimer's individuals who have behavioral issues. . . not just talking about wandering, but who are very angry, very, very aggressive, agitated, even assaultive. They do not fit in to nursing-home structure. What we need are small behavioral homes, group homes that would hopefully be funded under our TennCare Medicaid system - these individuals are shifted from a psych hospital to a nursing home, back to another hospital to another home.

**Comments from the Tennessee Alzheimer's Disease Task Force Public Hearing
June 16, 2008
Murfreesboro, Tennessee**

*most important thing we have is society that doesn't expect their healthcare professionals to screen them when they go for their annual physical for cognitive impairments, and it should become an essential piece of every physical exam that we have, is that we do some screening for cognitive impairment.

They need to do a depression assessment, too, because those are tied so closely together whether it's stressing or education health professionals or whether it's stressing and education the consumer to say, this is part of what you should be screening me for starting at whatever age, 40, 50, and every year I get this kind of screening done.

*Needs to be more information . . . given to the medical professionals.

*[day services are] an important resource that needs to grow in this State. . . . adult day services were the future for Tennessee because it's a cognitive-psych type program, and everybody is not left individually in their own household to deal with their dementia and sit on the sofa or watch television.

*we may need to kind of redefine some of what can occur in day care, because one of the issues in our geographic area is that is individuals require any assistance with toileting, they can't participate in the day program. . . . we're going to have to look at the restrictions that we use so that we don't keep many of the people who most need to be there in terms of socialization out because of care needs that could be met in those settings with some redesign.

*not enough day services, adult day program providers in the state or in our region for that matter.

*support groups have been a huge help. As soon as someone is diagnosed, if they could be referred to a support group in their area that seems to be very helpful for the family members as well as if it's early onset for the person who is diagnosed with the disease. We're just big advocates of the support groups.

*And so somehow there needs to be more education, better education with our legal departments in Tennessee so that they understand the significant need to help these families have the ability to help their moms and dads when it gets in that stage where the mom and dad can't speak for themselves. And Mobile Crisis doesn't have a passion for our senior citizens. They frequently look over them. . . . a lot of families struggle with . . . are Adult Protective Services. [Adult Protective Services] don't have the authority or the resources they need to be able to step up and help a senior. And the laws need to be tightened in the sense of protecting our seniors.

*the criticalness of s\dementia and what it's going to do in terms of impacting financially . . . the heart attack or the cardiovascular news may be very sudden and there's no more expense, but the dementia goes on for 15, 20 years, and the expense . . . it's very demanding on everybody. . . . we need to think outside the box and we need to spend our money thinking a little bit outside the box, . . . more education for all professionals about what they need to be doing a better job of doing with managing healthcare issues for the aging.

*through Diane's work and some others at the Alzheimer's Association, there's at least three early stage memory loss support groups in Tennessee now for the person with dementia who recognizes their symptoms, who has received their diagnosis and wishes to talk with other people about what they're going through. . . . Alzheimer's is not a selective disease. It affects all ethnic groups.

*Alabama had an innovative program there that the state had passed which was a Dementia Assessment and Research and Training Act that has some phenomenal educational materials, and they had nurses and other people who went out and did education across the state and also set up resource libraries in small communities.

*Concern that we've run into recently with the care of my mother and somewhat with Chris's dad is medical professionals honoring their written wishes in the forms of their living wills and advance directives.

*And one of the biggest voids that we see is lack of care management. There's lot of providers, . . . services, but unfortunately, . . . it's very hard for them to find the services and then it's hard to understand what the doctor is telling them what the medications are for, getting Mom to the doctor when they have to work full-time. . . . something else I think would be helpful, too, is assisted living. . . . the people . . . going in and out of the hospital, and in and out of the hospital for dehydration and malnutrition and end up in a nursing home that's not needed because basically they don't need that many services, but they don't have the money. It's financial issue. . . . it would really save the State a lot of money by not putting these people in a nursing home, but getting them to a facility similar to Knowles Home - tremendous gap with the assisted living.

*I think that PSAs and other things need to be put out there . . . put it out as information just like they do the drug issues and everything else . . . for help contact this number, and actually get it on the stations and have it listed in the phone book under "Elder Care" or something like that, and then just making sure that the people that answer . . . the lines . . . have all that information to refer out. . . . [nonprofits] need to look at yourself as a business and talk to some marketing people and say, How do we get this out there? . . . tremendous need . . . for elder care consults and finding information because . . . employers are finding employees losing work because of . . . taking care of parents and grandparents, so they want to fix that problem.

*[State] needs to look at other options like the adult day homes. They did make a trip to Oregon to look at the system out there.

*instead of focusing just on the people with Alzheimer's, reach out to the caregivers because they're the ones who can kind of backdoor in and get the people with Alzheimer's the care they really need or what's out there - you need to start hitting different age groups as to what's coming, because it is.

*we found really lacking is training for staff in Alzheimer's. . . . get some training out there for family members . . . beef up the training for staff, especially in assisted living . . . so many staff members . . . inappropriately approach the Alzheimer's patient, . . . activities are really, really poor, so far as Alzheimer's. . . . training for the families in Alzheimer's as well as

increasing the training for caregivers and caregivers in assisted living as much as in the nursing home.

*on the general units the lack of dementia education . . . when I ask the DONs what percentage of their population is dementia, they're telling me 70-80% of the general units, and the staff are just woefully unprepared.

**Comments from the Tennessee Alzheimer's Disease Task Force Public Hearing
June 17, 2008
Cookeville, Tennessee**

*a situation where regulations from different arms of care were different for the same illness . . . [grandmother] had Crohn's disease . . . Alzheimer's plus several health issues as well. . . . only time . . . to receive home based care regularly . . . was the physical therapy. . . . For Medicare to provide home-based services, a colostomy was not considered a nursing event. . . . when we looking for assisted living care, [the colostomy] was classified by the assisted living industry as a nursing event. And it was very confusing because the same exact nursing need . . . was classified differently by different arms of home health based care. . . . issue if the regulations don't match.

* just this week that there was going to be a requirement of license of these folks who are out in the community serving as sitters. I don't believe they're going to be able to pay I believe it's 800 and something dollars, 840, 850 a person for this licensure. And we are going to lose a lot of sitters and helpers in our community if this is correct - people who are sending out these lists [of sitters] and marking these sitters are possibly going to be fined.

*importance of respite care and the importance of offering those services. It is a very stressful job for caregivers. . . . I agree totally with the comments that the regulations - the State regulations with adult day services and assisted living and home based cares they need to match up and line up.

*need more education on early Alzheimer's. I was able to get my husband on the VA, otherwise, I wouldn't know where to go. And I still don't know where to go if I need help. I feel they should have some kind of register. . . . I had no clue what my needs were.

*need to address training and educating primary care physicians diagnosing properly and getting referrals.

*the neurologist in Kingsport, I was with mother when he said, there is no help for an Alzheimer's patient. He said, I have buried more caregivers than I have Alzheimer patients. So try to find somebody and get help. That was our help from the neurologist.

*sliding scale fee. There are middle-income people that don't qualify. Maybe they can pay some and they would get the benefit of some of the services that you all offer to lower income indigent folks. . . . needs to be encouraged funding for community awareness across the board, education and community awareness, and light caregiver workshops. . . . lot of preceptors to really getting that diagnosis. . . . family practitioners, nurse practitioners and our medical community need that education as well. But I think before that may here's a level of need for training and education with pastors and people in our religious community. . . . maybe some review or encouragement or assistance with cooperating with DHS as far as current State licensed facilities to be the Number 1 target to offer adult daycare. . . . recommendation that maybe there's current State licensed facilities might . . . give them the help they need to provide those services.

*people who have someone in their family who has been diagnosed with Alzheimer's but who aren't really aware of what they're facing or still at the point of not accepting this and knowing that they need to begin making plans and getting some support.

**Comments from the Tennessee Alzheimer's Disease Task Force Public Forum
June 30, 2008
Chattanooga, Tennessee**

*How are we going to educate our primary care physicians to recognize it. There's got to be some kind of outreach to do primary care physician education because early intervention is not being done, early diagnosis is not being done.

*treatment and diagnosis for Alzheimer's disease and elderly dementia should be a neurologist. It's an organic brain disease . . . not a psychiatric illness.

*My husband has early onset Alzheimer's. I wouldn't just wait and take him to my primary physician . . . I would get right onto it for someone who's an expert in the field.

*The doctor I took him to, who knew him very well and knew me very well, was not that concerned about it. . . . in a doctor's office, he could perk up and act like was just okay. . . I could tell at home he wasn't okay. . . gave him some medication . . . didn't refer him.

*not just a neurologist. You've got to find the right neurologist.

*[What] would be instrumental in helping get a good diagnosis is first and foremost, educating the public, educating doctors, educating nurses. . . . people in a medical environment had very little information as to what they were dealing with, and it seemed very simple to simply shut the door on a hospital room and forget that they were there. I don't fault them because I don't believe the education has been really pressed across our country. . . . when you're in the crux of this disease as a caregiver, it becomes totally all consuming, morning, noon and night, 24/7, 365 days of the year, if you multiply that out in the anxiety and the worry that you experience to be a caregiver.

*need in our community and all across our nation to educate primary care physicians.

*seems like people have the tag, we don't know what to do with an Alzheimer's person, especially someone that's in their very early 50's and it's painful

*Finances for home care is a real serious issue for families. . . . need adult daycare in these rural areas . . . need transportation in these rural areas.

we spend a lot on money financing people to go to the nursing home, and if we could get even half of that to keep them at home with a family caregiver's support, I think that would be helpful. . . . waiver program . . . is great but it's going to woefully fall short financially of providing what these families need.

*One of the things we can do for home health care is train caregivers. It takes a special person to take care . . . of any Alzheimer's disease patient. They need some special training.

*geriatric pharmacists are knowledgeable in the needs of geriatric patients. Seniors are at an increased risk for adverse drug events based on physiologic changes and aging, and dementia patients are at an even great risk due to the increased number of medications that these patients

are taking. . . . need someone to quarterback that and look and be a coordinator of care between the different prescribers that they see.

*adult day services is one thing for the rural communities. We live in a county where there's nothing there, nothing at all.

*very instrumental for the families and communities and throughout the state and the country is to have a help line.

*List of people who would actually sit with loved ones and the government actually help pay for it somehow. . . . 20 years in DC, cancer is everywhere, cancer's a bad disease but it's nothing, nothing compared to this. And we've been going 20 years and we're no farther along with having funding for it. This is ridiculous.

*If there was some kind of financial assistance, not limited to just people with Medicaid eligibility to help provide caregivers.

*I think one of the best services that our State could give people who have Alzheimer's disease and their families . . . is for the State to do it's job and to make nursing homes accountable for their quality of care. . . . Nobody listens to the ombudsman's complaints. Nothing was ever done to even address a complaint that people . . . were making through the Ombudsman Program.

*One thing that is right is Alzheimer's support groups.

*have a facility that looks after them, cares for them, and you do not have to worry about them if you are going or out of town.

*Most of the [nursing homes] I go to are built to make money, to look good, and they are not built for resident's care. . . . there's not enough help in the nursing homes. They don't pay enough.

*What's missing are group homes.

*One of the things that's missing in care and nursing homes, are the people really being trained to take care of Alzheimer's patients.

*more public service announcements, more education . . . public service education for early onset.

*more geriatric physicians.

*affordable services. You have to be impoverished or have lots of money to get help. So we've got to fix that. . . . another key services in single care coordination. . . . It's a pretty fragmented system.

*need to look at elder care law, and adult protective services. . . . Adult Protective Services program is not able to do a lot right now with the way the legal system has it locked in.

*had difficulty finding something for high-functioning patients to do during the day, some place for them to go.

*don't know how we're going to gear up for the care of us baby boomers as we're hitting that age. I think it's going to bankrupt families and systems and everything.

*When they're young, there's nothing out there for us

*have adult daycares at the nursing homes, where they don't have to stay overnight.

* it's important for you to understand the impact on the family and caregivers even when adequate care is available. . . . high level of stress . . . energy is taken away from my primary household . . . there's considerable distraction and loss of income from my employment. . . . of the following: Tax credits for family caregivers; educational programs for caregivers; reimbursement for family caregivers; support in the form of grants to non-profits.

*against the inpatient psychiatric programs in these hospitals that are concerned with medication management changes for elderly patients with dementia. . . . within a couple of days, my father declined tremendously, both from a cognitive and physical standpoint. . . . wrote a four-page letter to the administrator . . . did not ever get a response . . . Department of Health made an unannounced visit and told me in a letter later on that my complaints were substantiated. . . He's overmedicated. . . . against psychiatric-managed programs . . . neurologist should be managing it.

*we're dealing with two different disease. Young age is totally different than people dealing with their parents.

*my husband was aggressive. No place in Chattanooga would take him. . . . husband went to a nursing home. . . . We have no health insurance. He's on Medicare. I have nothing. I'm on my own. . . . strange things happen when you have a young person with Alzheimer's. . . . They just forget who you are, period. You're just a nobody. . . . Medicare, because my husband has not had a decline in the past two months is taking him off of hospice. Now, tell me what's fair in this world.

*there are many, many difficult situations that have not even been addressed here. One of the problems that people with Alzheimer's face in care facilities is abuse. . . . abuse by staff and even family abuse. Another problem is long-distance care giving. . . . still seems to be a stigma attached to this illness. . . . Because people don't know what to do, so they do nothing, which isolates the family and the care givers. . . . friends stop calling They don't know how to handle the pain and the difficulty of what the caregivers are experiencing. . . . care givers don't have the emotional energy to reach out, to ask for help.

*We've all been devastated by this disease. I think we have a common link, it's devastation . . . financially, emotionally, and spiritually. . . . It's going to cost us many trillions of dollars to deal with disease because my generation is coming up. There's 78 million of us. The numbers are staggering, the potential of what is ahead of us with this disease. . . . we need to rally and find somebody that can together a business plan and bring it to Washington and say, Folks, this is the impact. . . . education is primary and essential in dealing with this disease.

*There are good doctors and bad doctors; there are good nursing homes and bad nursing homes. And each of our experiences [is] individual. So I think it's important to look at that, too.

*concerned that we don't overlook the need for research in this field. . . . So I really hope in looking at initiatives, the State will include research and let's cure this disease.

*we're in an election year, and they are talking about all kinds of thing. And one of the things we don't hear a lot about health insurance programs.

*There is no way with government programs that I can spend \$613 a month for just one person's health insurance. . . . Something has to happen . . . if it's nothing else than informing those that are younger than us, you better start digging deep into your pockets and building up a lot of cash in the banks. But good luck on today's prices.

*almost like the rules out there for accessing TennCare almost force people to put their husband and wives in nursing homes. . . . the amount the spouses can keep is more, if they go in a nursing home than if they try to access community services. . . . Tennessee makes the spouse spend down more to access any services. . . . But within what federal law allows, Tennessee could do so much more for spouses at home and especially to make the access for community-based care the same as for accessing nursing home care.

*If we as a State can focus on wrapping services around our clients where they are, . . . We need to figure out how to wrap those services around individuals and families to that they don't feel it's a crisis moment. . . . focus on giving people services on the front end, then if a crisis happens, there will be a relationship and there will be those services where they know who to call and how to access the different services.

*whole continuum of care is very important . . . to make it possible for them to be as independent as possible for as long as possible through assisted living and then nursing home care.

*I'm beginning to put together how fragmented this industry is. I'm hearing people right and left say, I didn't know that and I didn't know that. We need some way to gather all the information together so we can understand early what we can do.

APPENDIX 5

Glossary of Acronyms and Definitions for Alzheimer's Disease and Related Dementia

Acronyms for Agencies, Organizations, and/or Programs

AA	Alzheimer's Association
AAAD	Area Agencies on Aging and Disability
AARP	formerly "American Association of Retired Persons"
AD	Alzheimer's Disease
ADARD	Alzheimer's disease and related dementia
ADRC	Aging and Disability Resource Center
APS	Adult Protective Services
BRFSS	Behavioral Risk Factor Surveillance System
PACE	Program of All-Inclusive Care for the Elderly
PWD	Persons with Dementia
TADAS	Tennessee Association of Adult Day Services
TAHC	Tennessee Association of Home Care
TCAD	Tennessee Commission on Aging and Disability
TDHS	Tennessee Department of Human Services
TDOH	Tennessee Department of Health
TDOT	Tennessee Department of Transportation
TDMHDD	Tennessee Department of Mental Health and Developmental Disabilities
THA	Tennessee Hospital Association
TMA	Tennessee Medical Association
TNAHSA	Tennessee Association of Homes and Services for the Aged
TRC	Tennessee Respite Coalition

Terms and Definitions

Accredited Facility: An accredited facility is a nursing home, assisted living center or hospital that meets very high standards of care. These standards are set by organizations such as the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO). To stay accredited, a facility must be inspected every 18 months to three years.

Adult Day: Care inside or outside the home provided for adults who require assistance with the *activities of daily living* or other largely non-medical supervision. But possibly including minimal medical-related services such as supervising the taking of medicine. Often includes social and recreational programs and, sometimes, occupational and physical therapy. Primarily intended for care during the hours that family members or other informal caregivers are at work, rather than care on a 24-hour basis.

Adult Day Facilities: Community based centers that provide comprehensive services ranging from health assessment and care to social programs for older persons who need some

Bill-Paying Services: Sloppy bill-paying behavior is one of the first things caregivers notice when they see a cognitive decline in their elderly parents or significant others. This often leads to a search for a commercial bill-paying service. Many banks also offer this service. While not exclusively for dementia patients, these services can make it much easier to assist a loved one with dementia to pay his or her bills and eventually, if necessary, to completely take over the task.

Care Assessment: This phrase is helpful to caregivers who seek professional guidance about how best to meet their loved ones' care needs.

Caregiver Burnout: This phrase describes a common feeling of helplessness and frustration among caregivers dealing with endless demands upon their time, energy, emotions, finances, and patience.

Caregiver Support Groups: Many caregivers cope with the loneliness and isolation of their situations by joining real or virtual support groups. The Internet can help them find an appropriate group.

Case Management: Case management describes the care and services planned by health care workers.

Centers for Medicare and Medicaid (CMS): Centers for Medicare and Medicaid is the government program that oversees nursing home care. CMS inspects nursing homes and enforces safety rules.

Certified Nursing Assistant (CNA); also Certified Nurse's Aide: A certified nursing assistant helps feed and care for disabled adults. To learn these skills, CNAs attend at least 75 hours of classes. A CNA works under a nurse's supervision and must keep taking classes to stay certified.

Charge Nurse: A charge nurse supervises the staff and residents of a floor or unit of a nursing home. The charge nurse's shift usually lasts eight hours. On each shift, day or night, a charge nurse should be available.

Chronic Care: Continuous, long-term care for persons suffering from chronic conditions. May be contrasted with acute care.

Custodial Care: Custodial care helps a person accomplish the activities of daily living (ADLs). Custodial care can also include preparing special diets and giving medications.

Deficiencies: Deficiencies are problems an inspector notes while visiting a nursing home or other facility. The facility must correct any deficiencies. Otherwise, it may be fined and dropped from Medicare or Medicaid participation.

Quality Indicators: Quality indicators describe the care in a long-term facility. For example, one quality indicator is the percent of residents whose need for help with daily activities has increased. The government's Nursing Home Compare Web site uses quality indicators to score every nursing home in the United States.

Recreational Therapist: A recreational therapist helps residents enjoy activities. For example, the recreational therapist might offer special tools, such as large-print song sheets, to encourage participation.

Resident: A resident is someone who lives in a long-term care facility, such as a nursing home.

Respite Care: Respite care provides temporary relief from care giving tasks. Such care could include in-home assistance, a short nursing home stay or adult day care.

Short-term memory: A system for temporarily storing and managing information required to carry out complex cognitive tasks such as learning, reasoning, and comprehension. Short-term memory is involved in the selection, initiation, and termination of information-processing functions such as encoding, storing, and retrieving data.

Skilled Nursing Care: This term refers to the highest level of professional medical care, characterized by 24-hour supervision by a registered or licensed practical nurse as ordered by a physician.

Skilled Nursing Facility (SNF): A facility licensed by the individual state, and one that may be certified by *Medicare*, providing care that requires the highest level of medical skills with continuous, 24-hour attention from a registered or licensed practical nurse, under a physician's orders and/or supervision. May also provide Intermediate or Custodial care and makes care available from other medical practitioners and for emergency services.

Social Worker: A social worker offers residents and their families therapy, support services and planning for discharge. Social workers may also teach and counsel staff members.

Staff-Resident Ratio: The staff-resident ratio compares the number of staff members to the number of residents they care for.

Survey: The state health department takes an unannounced survey of each nursing home about once a year. This survey helps make sure a facility is giving good care. A nursing home must participate to keep its license. Each facility has to post its latest survey results. These required surveys differ from the surveys of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) that a nursing home may request (see **Accredited facility**).

Vascular dementia: A type of dementia caused by brain damage from cerebrovascular or cardiovascular problems - usually strokes. It accounts for up to 20 percent of all dementias. Risk factors include high blood pressure, an unsteady way of walking, and advanced age. Symptoms include confusion, problems with recent memory, wandering or getting lost in familiar places,

loss of bladder or bowel control (incontinence), emotional problems such as laughing or crying inappropriately, difficulty following instructions, and problems handling money. The damage is typically so slight that the change is noticeable only as a series of small steps. However, over time, as more small blood vessels in the brain are blocked, there is noticeable gradual mental decline. Vascular dementia commonly begins between the ages of 60 and 75 and affects men more often than women. Also known as multi-infarct dementia..

Visuospatial Disturbances: A disturbance in the ability to comprehend and conceptualize the relationship between an object(s) seen and the space around it.

Young Onset Dementia: Young onset is the term used for those individuals diagnosed with Alzheimer's who are at an age younger than 65. It is a preferred term of the Alzheimer's Association to help clarify and avoid confusion with early stage Alzheimer's.

APPENDIX 6

Alzheimer's Disease and Related Dementia Websites

1. AARP

www.aarp.org

AARP is a nonprofit, nonpartisan membership organization for people age 50 and over. AARP is dedicated to enhancing quality of life for all as we age. We lead positive social change and deliver value to members through information, advocacy and service.

2. Alzheimer's Association

www.alz.org

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Its mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. This website includes links to local chapter who provide a variety of programs and services for people impacted by Alzheimer's disease.

3. Alzheimer's Association, Eastern Tennessee Chapter

www.alz.org/etn

The Eastern Tennessee Chapter of the Alzheimer's Association with offices located in Knoxville and Cookeville, Tennessee, provides support and assistance to individuals with Alzheimer's disease, their families, and care partners and supports research efforts to prevent, treat and cure Alzheimer's disease.

4. Alzheimer's Association, Mid-South Chapter

<http://www.alz.org/mid>

The Mid South Chapter of the Alzheimer's Association serves Northeast, Southeast, Middle and West Tennessee in addition to North Alabama. Offices are located in Tullahoma, Nashville, Johnson City, Chattanooga, and Memphis, TN. Their mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

5. Alzheimer's Disease Centers (ADCs) Directory. National Institutes of Health.

<http://www.nia.nih.gov/alzheimers/ResearchInformation/ResearchCenters>

Alzheimer's Disease Centers offer diagnosis and medical management; clinical research and drug trials; and information about the disease, services and resources.

6. Alzheimer's Disease Education and Referral Center (ADEAR)

<http://www.nia.nih.gov/alzheimers>

ADEAR maintains information on Alzheimer's disease research, diagnosis, treatments, clinical trials and federal government programs and resources. AD Lib, ADEAR's literature database, has nearly 8,500 materials related to Alzheimer's disease that includes fact sheets, textbook chapters, journal articles, brochures, teaching manuals, directories, videos and other media, bibliographies, program descriptions, monographs, newsletters and reports.

7. Alzheimer's Disease International (ADI)

<http://www.alz.co.uk>

ADI is an international membership group of Alzheimer associations. The ADI site links to member association sites throughout the world. It also provides information in several languages, statistics on the number of people with dementia worldwide, and the implications for the distribution of research funding, especially in developing countries.

8. Alzheimer's Foundation of America

<http://www.alzfdn.org>

The mission of the Alzheimer's Foundation of America is "to provide optimal care and services to individuals confronting dementia, and to their caregivers and families through member organizations dedicated to improving quality of life." The AFA's toll-free hotline provides information, counseling by licensed social workers and referrals to community resources across the nation.

9. Alzheimer Research Forum

<http://www.alzforum.org>

This Website reports on the latest scientific findings, from basic research to clinical trials; creates and maintains public databases of essential research data and reagents; and produces discussion forums to promote debate, speed the dissemination of new ideas, and break down barriers across the numerous disciplines that can contribute to the global effort to cure Alzheimer's disease.

10. Alzheimer Society of Canada

www.alzheimer.ca

The Alzheimer Society of Canada is a nationwide, not-for-profit health organization dedicated to helping people affected by Alzheimer's disease. The Society develops and provides support and educational programs for people with the disease, their families and their caregivers.

11. Alzheimer's Society UK

www.alzheimers.org.uk

The Alzheimer's Society is the UK's leading care and research charity for people with dementia and those who care for them. The Society provides information and support for those living with the disease, as well as training for professionals. The organization funds Alzheimer research and helps build awareness through its campaigning efforts.

12. ElderCare Locator

<http://www.eldercare.gov>

Eldercare Locator is a public service of the U.S. Administration on Aging. The Eldercare Locator is the first step to finding resources for older adults in any U.S community. The service links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers.

13. Family Care America

<http://www.familycareamerica.com>

The National Caregivers Library is one of the most extensive online libraries for caregivers that exist today. It consists of hundred of articles, forms, checklists and links to topic-specific external resources. The library is organized into the 18 Caregivers Resources categories, which appear to the immediate left on the screen.

14. Family Caregiver Alliance, Nation Center on Caregiving

<http://www.caregiver.org>

Family Caregiver Alliance (FCA), founded 30 years ago in 1977, serves as a public voice for these caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

15. Family Caregiving – It's Not All Up to You

www.familycaregiving101.org

This site is designed to provide caregivers with the basic tools, skills and information they need to protect their own physical and mental health while they provide high quality care for their loved one. It is also a place for family caregivers to return again and again as new levels of caregiving are reached.

16. Fisher Center for Alzheimer's Research

<http://www.alzinfo.org>

Fisher's site is a comprehensive portal for caregivers, family members, people living with Alzheimer's and the general public.

17. Mayo Clinic Alzheimer's Disease Center

<http://www.mayoclinic.com>

The Mayo Clinic Alzheimer's Disease Center has easy to understand, practical in-depth information on Alzheimer's and care giving.

18. National Alliance for Caregiving

<http://www.caregiving.org>

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency and corporations.

19. National Family Caregivers Association

<http://www.nfcacares.org>

NFCA offers virtual library of information and educational materials ranging from national educational campaigns to tips and guides for family caregivers, information on agencies and organizations which provide caregiver support, to communicating effectively workshops.

20. Tennessee Association of Adult Day Care Services (T.A.A.D.S.)

<http://www.taads.org>

The Tennessee Association of Adult Day Services was established in 1986 to provide support to those who provide a variety of day services to adults. Specific purposes include but are not limited to the following:

- Sharing information and exchanging ideas.
- Providing staff training to improve the quality of services.
- Promoting the public's understanding and support of day care for adults who need special care.
- Providing information and support to members about policies and procedures of state licensing.
- Promoting adult day services legislation to state officials and policy makers.

21. Tennessee Commission on Aging and Disability (TCAD)

<http://www.tennessee.gov/comaging>

The Commission is dedicated to working for adults with disabilities and older Tennesseans by providing leadership and guidance for a system that promotes health, dignity, independence and security through an array of community and in-home services, the protection of rights and the implementation of best practices. The Area Agencies on Aging and Disability (AAAD) serve as the single point for services in the community.

22. Tennessee Respite Coalition (TRC)

<http://tnrespice.org>

Respite is known as the gift of time. It allows families to continue their loving journey of care giving while maintaining their own health and well-being. TRC has four branches of service:

- **Respite Helpline:** a toll free number that families and professionals can call to get respite guidance, information and assistance.
- **Volunteer Respite:** working with Universities and community volunteers, the TRC delivers over 2500 volunteer hours of respite per year.
- **Regional Advocacy and Awareness:** the TRC is comprised of over two hundred member agencies that assist in getting information and assistance regarding care giving and respite to families
- **Family Directed Respite:** The TRC serves over 250 families each month with this family friendly approach to Respite services. This approach uses a voucher system and encourages families to feel in control and be empowered in their care giving responsibilities.

23. Tennessee Department of Health (TDOH)

<http://health.state.tn.us/>

This website provides information on health-related events, programs, funding opportunities, health alerts and recalls, and news updates for individuals, for those in need of health care, for health care professionals, for parents and for those in need of statistics and data.

24. Tennessee Department of Health, Division of Health Care Facilities

<http://health.state.tn.us/hcff/index.htm>

The Division of Health Care Facilities is responsible for ensuring quality of care in hospitals, nursing homes, ambulatory surgical treatment centers, and other kinds of health care facilities in Tennessee. The division licenses and/or certifies 21 types of health care facilities, including laboratories.

25. Tennessee Department of Mental Health and Developmental Disability (TDMHDD)

<http://www.state.tn.us/mental/>

The mission of TDMHDD is to plan for and promote the availability of a comprehensive array of quality prevention, early intervention, treatment, habilitation and rehabilitation services and supports based on the needs and choices of individuals and families served.