



THE DISTRICT OF COLUMBIA STATE PLAN ON ALZHEIMER'S DISEASE **2014-2019**





A Poem from an Alzheimer's Patient

DO NOT ASK ME TO REMEMBER,
DON'T TRY TO MAKE ME UNDERSTAND.
LET ME REST AND KNOW YOU'RE WITH ME,
KISS MY CHEEK AND HOLD MY HAND.

I'M SO CONFUSED BEYOND YOUR CONCEPT,
I AM SAD AND SICK AND LOST.
ALL I KNOW IS THAT I NEED YOU,
TO BE WITH ME AT ALL COST.

SO DO NOT LOSE YOUR PATIENCE WITH ME,
DO NOT SCOLD OR CURSE OR CRY.
I CAN'T HELP THE WAY I'M ACTING,
CAN'T BE DIFFERENT THOUGH I TRY.

JUST REMEMBER THAT I NEED YOU,
THAT THE BEST OF ME IS GONE.
PLEASE DON'T FAIL TO STAND BESIDE ME,
LOVE ME 'TIL MY LIFE IS GONE.

George Baskfield
(www.azuramemory.com)

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GOVERNMENT OF THE DISTRICT OF COLUMBIA
OFFICE ON AGING



Office of the Executive Director

November 1, 2013

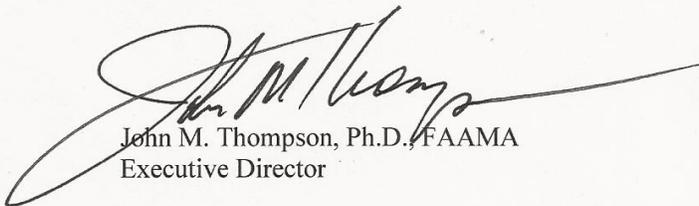
Dear Community Leader:

Among the numerous health problems that affect the citizens of the District of Columbia, Alzheimer's disease presents significant challenges for families, communities, and health care providers. In an effort to become a more Age-Friendly City, the Government of the District of Columbia is taking steps to address the issues that adversely impact the senior population and those who care about them. As the number of citizens with Alzheimer's disease continues to rise, the objective of the District of Columbia Office on Aging (DCOA) is to mitigate the effects of this disease and improve access to the necessary benefits in a timely and appropriate manner.

The District of Columbia Alzheimer's Disease State Plan is designed to focus all of the city's available resources on a set of measurable goals intended to improve the lives of those living with Alzheimer's disease and reduce the burden on caregivers. We realize that this is a complex problem that will take time to address; therefore, we have prepared a 5-year plan to phase in several action tasks that range from simple short-term solutions to intricate multi-year efforts requiring large scale collaboration between various partners.

By seeking input and contribution from various stakeholders, DCOA's objective is to increase awareness and improve the following aspects of Alzheimer's disease care: Research and Data, Quality of Care, Public Outreach and Awareness, and Training and Workforce Development. We welcome input and assistance from both private and public institutions, as well as those who want to help on an individual level. By working together on Alzheimer's disease and other chronic illnesses, we hope to realize our vision of making the District of Columbia an Age-Friendly City and enhance the quality of life for seniors, persons living with Alzheimer's disease, and all residents of the District of Columbia.

Sincerely,



John M. Thompson, Ph.D., FAAMA
Executive Director

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EXECUTIVE SUMMARY

Alzheimer's disease is the most common form of dementia, a general term for memory loss and other intellectual abilities serious enough to interfere with daily life. Alzheimer's disease accounts for 50 to 80 percent of dementia cases. The following Alzheimer's Disease State Plan was prepared by the District of Columbia Office on Aging (DCOA) in consultation with community partners and stakeholders throughout the District. The plan was developed to ensure that individuals diagnosed with Alzheimer's disease and their caregivers receive the support they need and reduce the burden that often accompanies Alzheimer's disease and other related diseases. Alzheimer's disease, the most common form of dementia, affects an individual's memory, behavior, and ability to think clearly. The disease is a source of emotional and financial stress for patients and family members who provide the majority of support for those living with Alzheimer's disease. With the number of cases continuing to rise, the need for care is becoming increasingly important.

This plan is not intended to be a panacea for Alzheimer's disease. Rather, this is an outline to reduce the negative impacts and corral as many resources as possible to support those who need assistance. In addition, the document includes a plan to increase outreach so that more people are aware of the disease and how to recognize the symptoms. Although this plan was prepared by a government agency, the execution requires collaboration from the community as a whole so that all the available stakeholders are aligned in their thinking. Including all stakeholders in the process is necessary to eliminate or at least reduce conflicts of interest and contradictory information.

The plan includes four major categories: Research and Data, Quality of Care, Public Outreach and Awareness, and Training and Workforce Development. Each section is separated into three sub-sections: Short Term, Mid Term, and Long Term. The Short Term sections refer to goals that should be completed within one to two years. Mid Term goals should be completed in two to three years, and Long Term goals should be completed in three to five years. This plan is intended for use by DCOA and other District government agencies as well as non-profit organizations, hospitals, universities, citizens, caregivers, etc. The plan is detailed without being overly specific, which allows for new ideas to be adopted and each recommendation to be updated as new research becomes available. However, this is the current plan and provides our roadmap for the next five years.

WHY IS THE PLAN NEEDED?

According to the National Center for Health Statistics (NCHS, 2008), the mortality trend for Alzheimer’s disease is rapidly increasing. In 2008, an American developed Alzheimer’s disease every 68 seconds. Experts estimate that by 2050, an American will develop the disease every 33 seconds. From 1979 to 1998, the rate for Alzheimer’s disease increased dramatically because of factors such as improvements in diagnosis and awareness of the condition within the medical community. The transition from International Classification of Diseases (ICD)-9 to ICD-10 brought substantial changes to the coding and selection rules for this condition, which created a major disruption in the time series trend for Alzheimer’s disease between 1998 and 1999. The large increase in the Alzheimer’s disease mortality between 1998 and 1999 is partly due to the ICD transition (NCHS, 2001). However, more recent increases may be attributed to growth in the elder population.

The number of Americans with Alzheimer’s disease and other related diseases is expected to grow as the U.S. population age 65 and older continues to increase. By 2025, this population is estimated to reach 7.1 million—a 40 percent increase from the 5 million in this age group who are currently affected. By 2050, the number may nearly triple, from 5 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent, slow, or stop the disease.

Scientists now suggest that you can stimulate your mind, improve your mood, sharpen your memory, and reduce your risk of developing Alzheimer’s disease and other related diseases (HelpGuide, 2009). Although you cannot change your inherited genes, ethnicity, gender, or age, you can change behavior and respond to known contributors of the disease. Some conditions and behaviors that may increase the risk of developing Alzheimer’s disease have been identified:

- diabetes
- hypertension
- high blood cholesterol
- heart disease
- obesity
- chronic stress
- poor quality or insufficient sleep
- sedentary lifestyle
- liver disease
- smoking
- alcohol and drug use
- kidney disease
- head injury
- damage to brain cells

Although there are no magic solutions, new evidence suggests it may be possible to prevent or delay the onset of Alzheimer’s disease through a combination of healthful habits. The following factors necessitate the preparation of a prevention and treatment plan of action:

- Alzheimer’s disease and other related diseases have been frequently misdiagnosed.
- More home and community-based services are needed.
- Long-term services and supports systems (LTSS) need improvements.

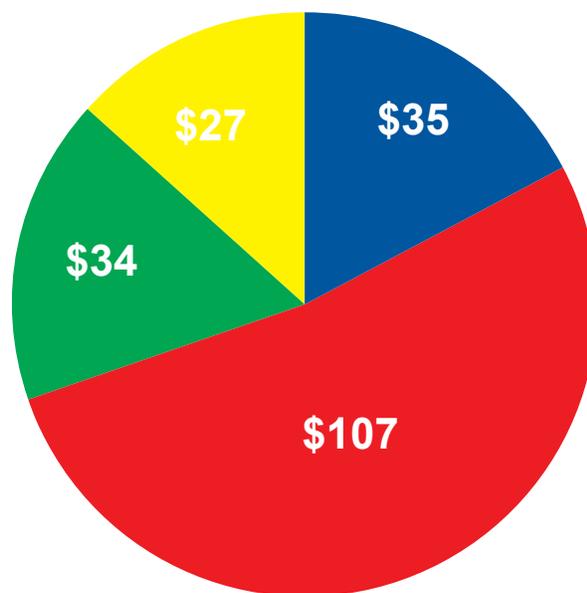


- Costs associated with increased hospital readmissions and premature nursing home admissions can and should be prevented.
- Person-centered/humanistic approaches in helping adults diagnosed with Alzheimer’s disease remain in their communities for as long as possible are becoming more popular.
- The U.S. Department of Health and Human Services recently announced a grant to promote dementia-capable models.
- Today, at least 50,000 volunteers, both with and without Alzheimer’s disease, are urgently needed to participate in more than 175 active clinical trials and studies in the United States.
- Alzheimer’s disease adversely impacts caregivers, families, and communities physically, mentally, socially, and economically.
- Family caregivers reported poor mental health and physical strain due to being overworked because of caregiving, taking care of a family, and maintaining a job.
- Caregivers are sacrificing their normal lifestyles to take care of dependent family members. For example, many are foregoing the opportunity to enjoy social events and school activities because of the demands of caring for a loved one with dementia.
- Many families lack support and money for services.

STATISTICS

- 75 percent of persons with dementia may be undiagnosed.
- One in 10 persons over the age of 65, and nearly half of those over the age of 85, have Alzheimer's disease
- Alzheimer's disease can develop in people who are in their thirties or forties, but that is extremely rare. The majority of people with early-onset Alzheimer's disease are in their fifties or early sixties.
- Only 5-10 percent of people diagnosed with Alzheimer's disease are younger than 65.
- One out of seven people with Alzheimer's disease and other related diseases live alone (WebMD, 2012).

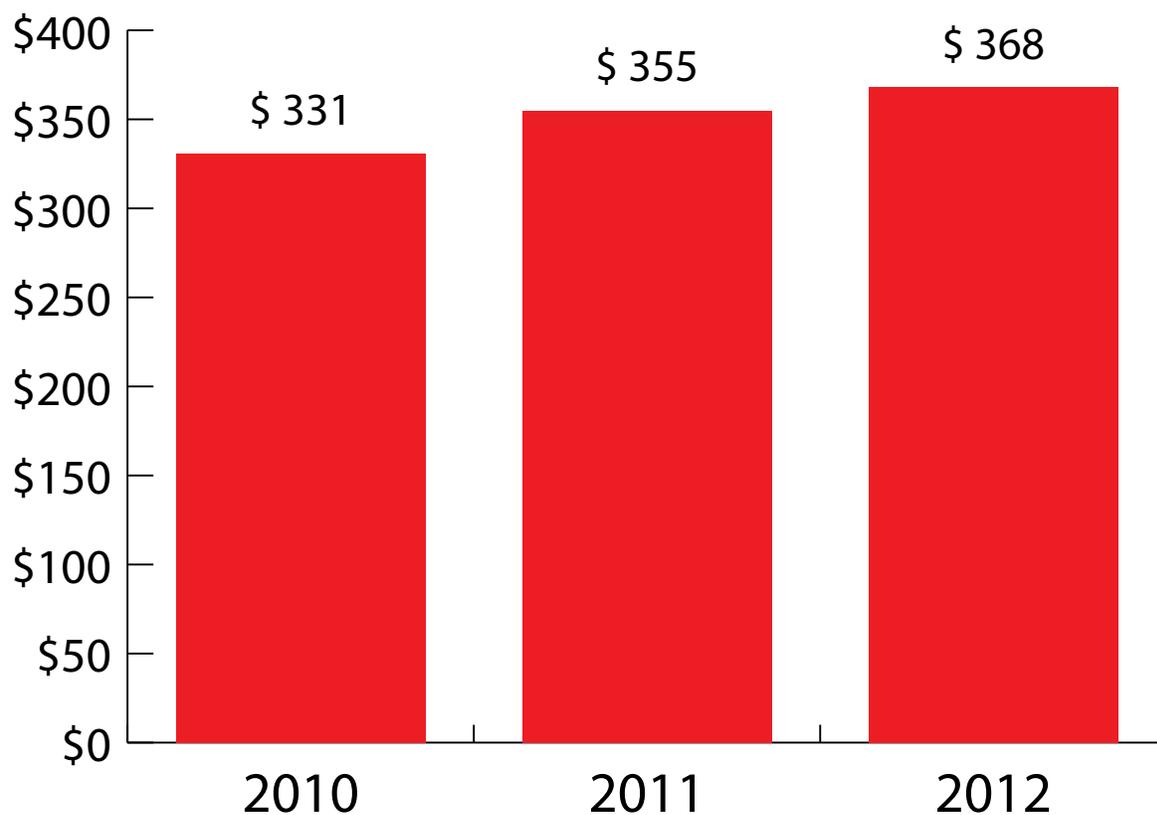
Costs of Alzheimer's Disease in U.S. (Billion)



Data: *Alzheimer's Association (2013)*

- 70 percent of people with Alzheimer’s disease live at home, where family and friends provide most of their care and pay for it out of their own pockets (Alzheimer’s Association, 2013).
- The treatment of Alzheimer’s disease and other related diseases is approximately \$200 billion annually (Web MD, 2012).
- Institutional settings (assisted living facilities, group homes, and nursing homes) cost approximately \$110,000 annually per person.
- Home and Community-Based Services (HCBS) (respite programs, adult day care, peer group support, and home health services) cost \$35,000 annually per person.
- Caregivers missing work costs the U.S. economy an estimated \$25.2 billion in lost productivity due to absenteeism.
- Family caregivers are credited with providing \$450 billion of unpaid services to loved ones annually in 2009. This represents a \$75 billion increase from \$375 billion in 2007 (Family Caregivers Alliance, 2013).

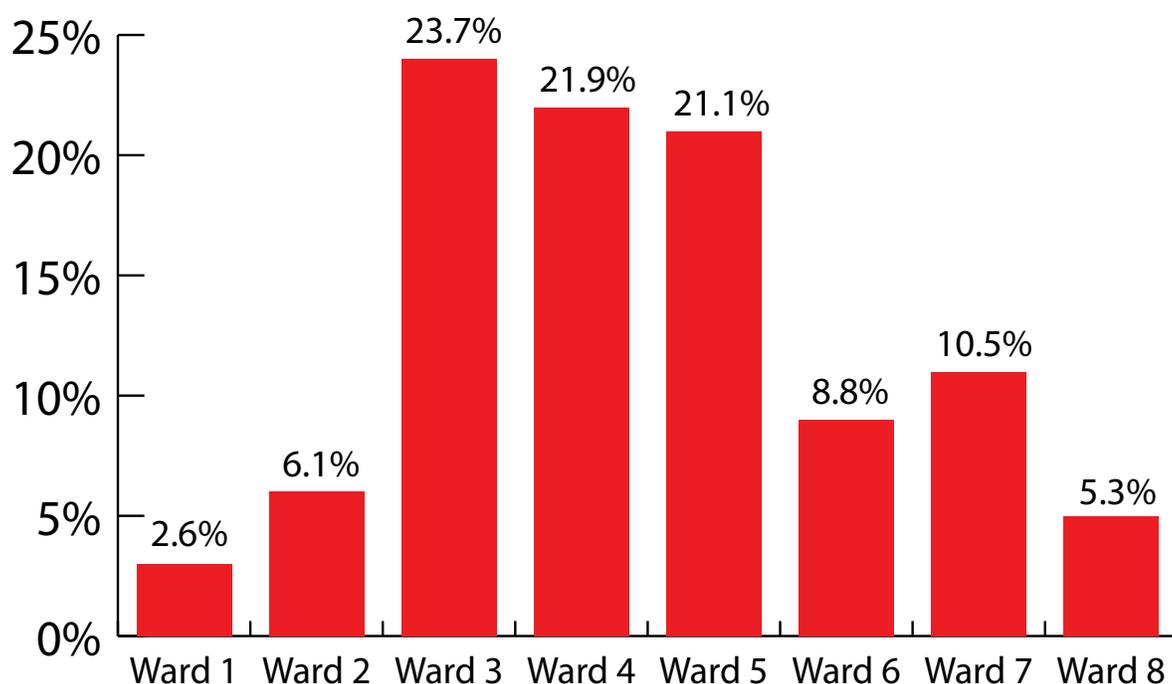
Cost of Unpaid Alzheimer’s Disease Care in D.C. (Million)



Data: *Alzheimer’s Association (2013)*

- Family caregivers accounted for \$368 million of unpaid services to loved ones in 2012 in the District of Columbia (Alzheimer’s Association, 2013).
- African-American and Hispanic caregivers are significantly more likely (37 percent versus 33 percent than caregivers of other races (23 percent) to believe that Alzheimer’s disease is a normal part of the aging process (No Time to Waste: Recommendations for an Integrated Plan to Overcome Alzheimer’s Disease; Alzheimer’s Foundation of America, October 2011).
- In 2010, there were 114 deaths in which the cause of death was listed as Alzheimer’s disease in the District of Columbia.

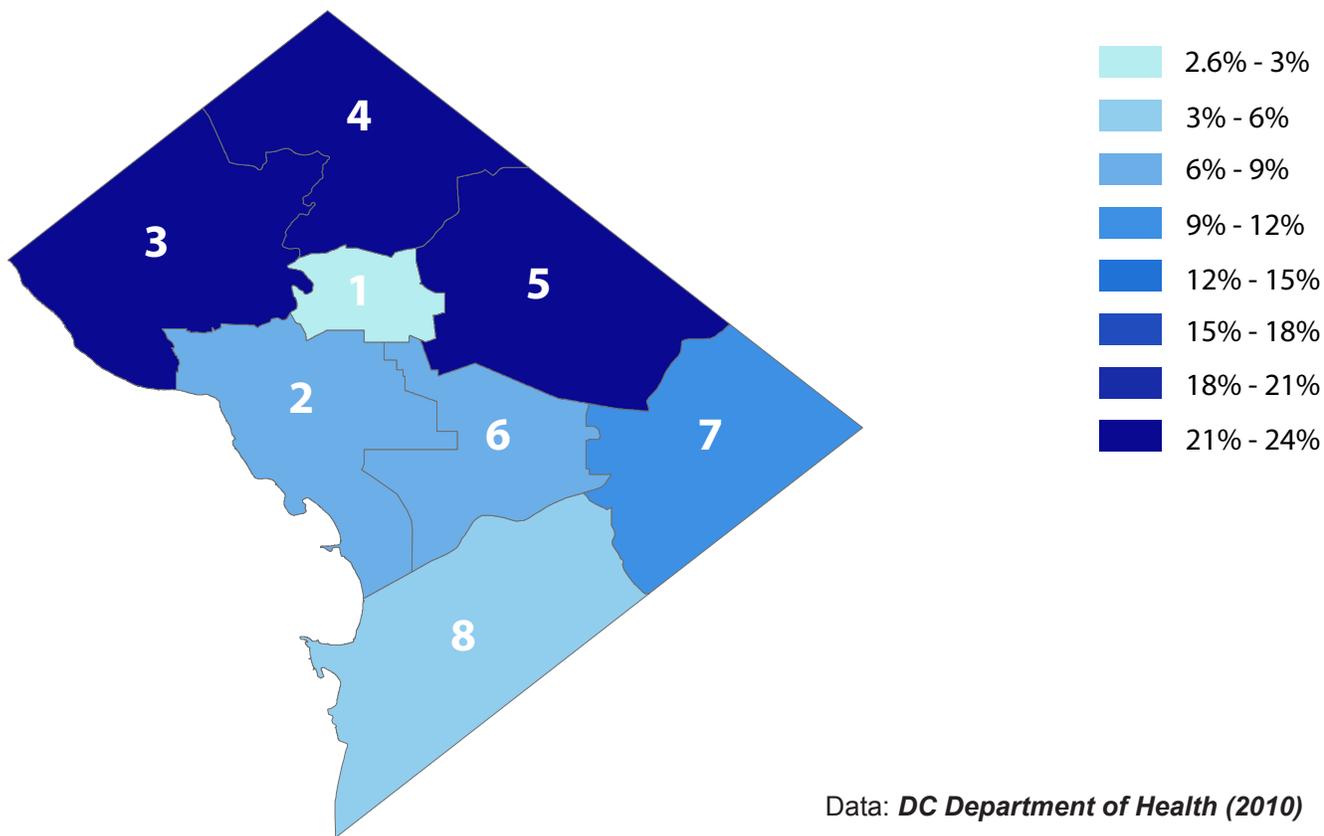
Percentage of Alzheimer’s Disease Deaths by Ward



Data: *DC Department of Health (2010)*

- Approximately 9 percent of the District of Columbia’s senior population has been diagnosed with Alzheimer’s disease (Alzheimer’s Association, 2013).
- Alzheimer’s disease was the 6th leading cause of death in the United States in 2010.
- Alzheimer’s disease was ranked the 9th leading cause of death in the District of Columbia in 2010 with an age-adjusted rate of 20.3 per 100,000 population.
- Ward 3 had the highest mortality rate of 35.0 per 100,000 compared to Ward 1, which had the lowest mortality rate (3.9 per 100,000).

Percentage of D.C. Alzheimer's Disease Deaths by Ward



GOALS

Research and Data

Short Term

1. Identify all organizations and institutions in the District of Columbia involved in Alzheimer's disease research to promote Alzheimer's disease research awareness and strategic alliances.

Rationale - Identifying all organizations and institutions in the District of Columbia involved in Alzheimer's disease research will allow for the collection and banking of research completed by Alzheimer's disease organizations and institutions in the District of Columbia. This strategy will also promote Alzheimer's disease research awareness and strategic alliances among experts in the field. Additionally, the consolidation of information, along with partnerships of key stakeholders, will allow for the short-term task of disseminating information to the public about Alzheimer's disease.

Responsible Parties - Nonprofits, Universities, Research Institutes, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions

2. Inform the public of Alzheimer's disease by identifying and disseminating existing research and data to residents in the District of Columbia.

Rationale - We expect all organizations and institutions involved with Alzheimer's disease research to collaborate and consolidate information pertaining to Alzheimer's disease. This consolidated information will then be disseminated in each Ward of the District of Columbia. Documents will be produced in English, Spanish, French, Chinese, Vietnamese, and Amharic. These materials will be Ward specific in an effort to be culturally sensitive and informative to all residents in the District of Columbia.

Responsible Parties - Alzheimer's Association Medical and Scientific Advisory Council (MSAC), Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART), Health Care Professionals, Nonprofits, Universities, Research Institutes, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions

3. Promote and support innovative Alzheimer's disease research by increasing the sharing of knowledge and innovative research methods through standalone conferences and by incorporating Alzheimer's disease research topics into other conferences occurring in the District of Columbia.

Rationale - We expect researchers to acquire more knowledge and establish relationships with those conducting similar or revolutionary Alzheimer's disease research through the promotion of local and national conferences and workshops pertaining to Alzheimer's disease research. In these forums, stakeholders in Alzheimer's disease research will have the opportunity to network and develop partnerships and share ideas. Researchers will be encouraged to include traditional as well as alternative/natural treatment methods. The implementation of these conferences and workshops is expected to begin by September 2014.

Responsible Parties - Federal and State Agencies, Scientists, Student Researchers, University Professors, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions

4. Implement the cognitive impairment module in the Behavioral Risk Factor Surveillance System (BRFSS) to 4,800 District of Columbia residents 18 years and older in all eight (8) Wards of the city. Provide BRFSS data findings to the Alzheimer's Association.

Rationale - Data findings will provide more insight on the depth of Alzheimer's disease related to difficulties in thinking or remembering that can make a difference in District of Columbia residents' everyday activities. This short term goal is expected to be implemented by September 2014.

Responsible Parties - Department of Health/Behavioral Risk Factor Surveillance System (BRFSS), National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions

Mid Term

5. Increase participation of at risk populations in clinical research trials through the exploration and implementation of campaign methods.

Rationale - The District of Columbia plans to increase participation of at-risk populations in clinical trials regarding Alzheimer's disease and other related research. It is expected that the promotion and sharing of information to residents in all Wards of the District of Columbia, through advertisement and dissemination of research directories, will increase participation of at-risk populations in clinical research. This task is expected to occur within the first 2-3 years of the D.C. Alzheimer's Disease State Plan implementation.

Responsible Parties - D.C. Office on Aging, Aging and Disability Resource Center (ADRC), Federal and State Agencies, Health Care Professionals, Private Insurance Companies, Medicaid/Medicare, Local Universities, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, Faith Based Organizations, Community Advocates, and other appropriate organizations & institutions

Long Term

6. Establish a Coordinating Council to advocate for increased private, corporate, and philanthropic funding for Alzheimer's disease research through collaboration of the District of Columbia's research community/ organizations.

Rationale - Through the implementation of this strategy, we expect to see an increase in private, corporate, and philanthropic funding. Moreover, proposing new legislation to secure government funding for Alzheimer's disease research will be an effective means of attracting and maintaining Alzheimer's disease researchers to the District of Columbia. This task is expected to be ongoing throughout the entire length of the District of Columbia's 5-year State Plan.

Responsible Parties - The Alzheimer's Association International Research Grant Program and Private, Corporate, and Philanthropic Organizations, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions

Quality of Care

Short Term

1. Collaborate with mental health professionals, home health care professionals, and legal professionals to develop, re-evaluate, and update a process/protocol to permit persons with Alzheimer's disease and other related diseases to remain in their current living environment. This would include providing safety checklists to caregivers and conducting home assessments to ensure the safety of the living environment.

Rationale - This action is intended to allow persons with Alzheimer's disease and other related diseases to have options regarding the services they receive. Encouraging more people to age in place will reduce the need for institutional placement.

Responsible Parties - D.C. Office on Aging, D.C. Department of Behavioral Health, DHCF, Senior Service Network, Alzheimer's Foundation of America (AFA), AARP, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions

2. Provide face-to-face and online training to hospital and nursing home staff, first responders, home care providers, senior housing staff, federal/local agencies, and transportation services through collaboration with the lead agencies of the DC Office on Aging and other local agencies.

Rationale - People with Alzheimer's disease and other related diseases rely on physicians and other healthcare professionals to provide them with current information and treatment options. Individuals receiving training will gain accurate knowledge of information and available services to persons with Alzheimer's disease and other related diseases. People with this disease may display disruptive or aggressive behaviors that are sometimes misunderstood. This training will also allow the professionals to more accurately identify individuals with Alzheimer's disease and other related diseases, ensuring that their rights are preserved and incidents of abuse, neglect, and exploitation are prevented.

Responsible Parties - D.C. Office on Aging, Alzheimer’s Foundation of America (AFA), National Alliance on Mental Illness (NAMI), Caregivers, Local Nursing Homes, Local Hospitals, Federal Agencies, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

3. Expand community based social programs for people experiencing onset symptoms of Alzheimer’s disease.

Rationale - Individuals experiencing cognitive impairment caused by the early stages of dementia need a safe environment where they can socialize without suffering the stigma of having decreased levels of mental ability. People should be able to maintain their dignity and continue to build friendships as their mental abilities begin to decline. Participants will engage in person centered activities designed to combat long term memory loss. They will also be able to share experiences with peers in a safe environment.

Responsible Parties - D.C. Office on Aging, Alzheimer’s Foundation of America (AFA), National Alliance on Mental Illness (NAMI), Caregivers, Local Nursing Homes, Local Hospitals, Senior Service Network, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, Faith Based Organizations, Community Advocates, and other appropriate organizations & institutions

Mid Term

4. Identify ways to engage in meaningful activity for those living with Alzheimer’s disease and other related diseases.

Rationale – Purpose for living is like medicine. Including those with Alzheimer’s disease in all the regular daily life activities – cooking while supervised, cleaning, laundry, gardening, etc. would do a world of good. Individuals who maintain a greater sense of purpose in life as they age may have great protection against Alzheimer’s disease, researchers have found. Those with a purpose had more than a 50 percent reduced risk of the disease, Dr. Patricia A. Boyle of Rush University Medical Center in Chicago and colleagues reported in the March 2010 issue of the Journal Archives of General Psychiatry. “The tendency to derive meaning from life’s experiences and to possess a sense of intentionality and goal directedness are associated with a substantially reduced risk of Alzheimer’s disease and a less rapid rate of cognitive decline in older age,” the researchers wrote.

Responsible Parties - D.C. Office on Aging, Alzheimer’s Foundation of America (AFA), National Alliance on Mental Illness (NAMI), Caregivers, Local Nursing Homes, Local Hospitals, Senior Service Network, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, etc.

5. Explore electronic/virtual monitoring tools in the home to support caregivers and increase the safety of those with Alzheimer's disease and other related diseases.

Rationale – Workforce shortages limit access to care and support. The desire of some affected persons to be alone all or part of the time should be accommodated when appropriate. Electronic/virtual monitoring can extend access to care and support when providers are not available and can also be used to ensure the safety of those with Alzheimer's disease when they wish to be alone.

Responsible Parties - D.C. Office on Aging, Alzheimer's Foundation of America (AFA), National Alliance on Mental Illness (NAMI), Caregivers, Local Nursing Homes, Local Hospitals, Senior Service Network, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, etc.

6. Collaborate with responsible parties to provide person-centered support services for caregivers and persons with Alzheimer's disease and other related diseases.

Rationale - Persons and families directly affected by Alzheimer's disease and other forms of dementia often feel overwhelmed. Training and support is needed for caregivers and adult day care centers through monthly, weekend family caregiver support and respite programs. For persons dealing with Alzheimer's disease or other related diseases, a support group will decrease isolation, reduce distress, and empower the patient as well as the caregivers and family members.

Responsible Parties - D.C. Office on Aging, D.C. Department of Behavioral Health, Alzheimer's Foundation of America (AFA), National Alliance on Mental Illness (NAMI), Caregivers, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions

7. Provide mental health services to persons with cognitive challenges and caregivers including but not limited to individual counseling, crisis counseling, family therapy, group therapy, support groups, and individual therapy.

Rationale - People and families directly affected by Alzheimer's disease and other related diseases often experience a wide range of emotions. Providing the appropriate counseling services is essential for those struggling to cope with the effects of Alzheimer's disease. We plan to provide counseling services in ideal settings (counselor's office, in home, outpatient clinic, hospital, residential treatment center), where patients can receive all the required services in the most convenient and least disruptive manner possible. Counseling services allow people to realize that they are not alone and will improve the overall mental health of both the caregiver as well as the person living with Alzheimer's disease and other related diseases.

Responsible Parties - D.C. Office on Aging, D.C. Department of Behavioral Health, Patients, Caregivers, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, Faith Based Organizations, Community Advocates, and other appropriate organizations & institutions

8. Provide education and assistance to persons living with Alzheimer’s disease and caregivers regarding legal, medical, and financial decisions such as establishing power of attorney or legal guardianship.

Rationale - Often, persons with Alzheimer’s disease and other related diseases are unable to manage their own legal, medical, financial, and healthcare affairs. It can often become overwhelming and confusing to those with dementia and their families when it comes to handling these important matters. Providing education and assistance in this area will allow people with dementia to become involved in their own care, granting them a sense of empowerment, and reduce conflict/stress on caregivers.

Responsible Parties - D.C. Legal Aid Society, Consumer Protection Bureau, Legal Counsel for the Elderly, Other Legal Professionals, Patients, Caregivers, Long-Term Care Ombudsman’s Office, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

Long Term

9. Develop promising dissemination methods through collaboration with a stakeholder network for sharing of information and ideas.

Rationale - Identifying promising practices for persons with Alzheimer’s disease and other related diseases will provide evidence-based recommendations for the care of these persons. This will ensure that quality of care is accurately measured and that improvement tools are implemented, resulting in improved and overall quality of care of these individuals.

Responsible Parties - D.C. Office on Aging, Alzheimer’s Foundation of America (AFA), National Alliance on Mental Illness (NAMI), Federal Government Agencies, Caregivers, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

Public Outreach and Awareness

Short Term

1. Create Alzheimer's disease support groups through collaboration with the D.C. Department of Behavioral Health, the Alzheimer's Foundation of America (AFA), the National Alliance on Mental Illness (NAMI), and hospitals within the District of Columbia with the intent of constructing and facilitating peer support groups for persons affected by Alzheimer's disease and other related diseases.

Rationale – Organizing a support group focused on Alzheimer's disease and other related diseases will create stimulating interaction among peers. In this group environment, participants can discuss diverse ideas and opinions. By sharing personal experiences and expressing ideas, members of the support group are able to explore various options for providing better quality care. For each person dealing with Alzheimer's disease or other related diseases, a support group will decrease isolation, reduce distress, and empower the support group as much as each member. In building this support system, each member will gain further understanding of the disease from which the individual is suffering, become more aware of what to expect as the disease advances, and acquire knowledge of the resources available to them.

Responsible Parties – D.C. Office on Aging, D.C. Department of Behavioral Health, Alzheimer's Foundation of America (AFA), National Alliance on Mental Illness (NAMI), National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, Faith Based Organizations, Community Advocates, and other appropriate organizations & institutions

2. Collaborate with government and community partners to identify means of providing an information line or 24/7 Alzheimer's disease support helpline for the general public, particularly caregivers and health care providers.

Rationale – A helpline in the District of Columbia for Alzheimer's disease and other related diseases will create an environment that provides accessibility to information and referrals and promotes knowledge about the disease among District residents and health care providers.

Responsible Parties – D.C. Office on Aging, D.C. Adult Protective Services, Health Care Providers, Long-Term Care Ombudsman's Office, Alzheimer's Foundation of America, AARP, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions

3. Incorporate electronic links within supported District of Columbia websites to ensure that reliable information from District of Columbia agencies is disseminated.

Rationale – Since the District of Columbia lacks a centralized resource center for Alzheimer's disease and other related diseases, DCOA will promote access to information and referrals to health care providers and caregivers through the linkage of multiple websites which focus on health and wellness for persons with Alzheimer's in the District of Columbia. By doing so, DCOA will generate additional traffic to these web sites and increase awareness of Alzheimer's disease and other related diseases.

Responsible Parties – D.C. Office on Aging, Adult Protective Services, Health Care Providers, Long-Term Care Ombudsman’s Office, Alzheimer’s Foundation of America, AARP, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

4. Disseminate appropriate content to all demographic populations in District of Columbia in Wards 1 through 8, promoting positive images of caregivers and people living with Alzheimer’s disease and other related diseases.

Rationale – Improved knowledge, information, and awareness will garner a two-fold, positive impact throughout District of Columbia communities. First, a public campaign will reduce the stigma associated with Alzheimer’s disease and other related diseases. In addition, the distribution of information on Alzheimer’s disease and other related diseases will encourage communities to engage in activities and a healthy lifestyle that stymie the onset of the disease.

Responsible Parties – D.C. Office on Aging, Health Care Providers, National Bureau of Statistics, Center for Disease Control, U.S. Census Bureau, American Community Survey, Senior Wellness Centers, AARP, D.C. Department of Health, U.S. Department of Health and Human Services, Broadcast Companies, Local Radio Stations, Print/Online Publications, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

5. Disseminate appropriate content in District Wards 1 through 8 that provides information on a brain-healthy lifestyle including: exercise, nutrition, cognitive activity, and social engagement as key protective factors against Alzheimer’s disease and other related diseases.

Rationale – A healthy brain is dependent on and maintained through physical and mental activity, as well as good nutrition. Prevention measures for Alzheimer’s disease and other related diseases include controlling blood pressure, cholesterol, and weight levels by exercising both body and mind, maintaining a low fat diet including fruits and vegetables, and engaging in leisure activities in social settings that emphasize physical and mental fitness.

Responsible Parties – D.C. Office on Aging, Health Care Providers, National Bureau of Statistics, Center for Disease Control, U.S. Census Bureau, American Community Survey, Senior Wellness Centers, AARP, D.C. Department of Health, U.S. Department of Health and Human Services, Broadcast Companies, Local Radio Stations, Print/Online Publications, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

Mid Term

6. Compile resources devoted to Alzheimer’s disease and other related diseases and develop resource guides for caregivers, health care professionals, family members of those suffering from Alzheimer’s disease, and senior service networks.

Rationale – A resource guide on Alzheimer’s disease and other related diseases will identify key resources and provide a simplified compilation of community services focused on the disease. It will also serve as a quick reference for the public.

Responsible Parties – D.C. Office on Aging, D.C. Department of Human Services, D.C. Department of Health, Center for Disease Control, Long-Term Care Ombudsman’s Office, National Institute on Aging, National Association of States United for Aging and Disabilities, National Association of Area Agencies on Aging, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

7. Develop content for public awareness campaigns addressing issues pertinent to Alzheimer’s disease and other related diseases, including the early signs and effective strategies for obtaining diagnosis, treatment, and support. The campaign will also include the cost of care, health insurance limits, end-of-life care options, and appropriate use of advance care directives.

Rationale – A public awareness campaign will educate the public and encourage prevention among communities that are at risk of developing Alzheimer’s disease and other related diseases.

Responsible Parties – D.C. Office on Aging, D.C. Department of Human Services, D.C. Department of Health, Center for Disease Control, Long-Term Care Ombudsman’s Office, National Institute on Aging, National Association of States United for Aging and Disabilities, National Association of Area Agencies on Aging, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

8. Promote the early detection of Alzheimer’s disease and other related diseases by implementing a campaign that provides information on the seven (7) stages of Alzheimer’s disease. Establish partnerships with businesses and community service groups. Educate and enlist villages and the faith-based community in reaching out to and supporting family caregivers and people living with Alzheimer’s disease and other related diseases.

Rationale – Early detection of Alzheimer’s disease and other related diseases buffers stressors typically associated with the diagnosis. Timely detection enables access to information, maximizes quality of life, and provides assistance to families when preparing for the future. An early detection campaign in conjunction with local businesses, religious organizations, and community support groups, will improve community conversations and support thereby, reducing the stigma related to Alzheimer’s disease and providing a sense of empowerment to those affected by the illness. Villages and the faith-based community are an under-utilized avenue for promoting a healthy lifestyle, in spite of their presence, longevity, and influence in the community. Through a public awareness campaign within that community, DCOA will reach populations both least and most at risk of developing Alzheimer’s disease and other related diseases.

Responsible Parties – Health Care Providers, D.C. Department of Human Services, Mental Health Professionals, Office of Religious Affairs, Faith-Based Organizations, Center for Medicare/Medicaid Services, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

9. Increase awareness and establish a campaign among District of Columbia residents that encourages residents to take advantage of cognitive screenings which are included in yearly wellness examinations under Medicare/Medicaid services.

Rationale – According to the Alzheimer’s Foundation of America, cognitive screenings are included in yearly wellness examinations administered through Medicare/Medicaid services. The screenings have gained minor traction because physicians fail to enforce the examination, and patients are unaware that it is included in their insurance plans. Through an awareness campaign, the public will be informed of and encouraged to ask their physicians to perform this very important part of a yearly wellness examination.

Responsible Parties – Health Care Providers, D.C. Department of Human Services, Mental Health Professionals, Office of Religious Affairs, Faith-Based Organizations, Center for Medicare/Medicaid Services, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

10. Initiate a diverse working group of community organizations to bring greater awareness to Alzheimer’s disease and other related diseases by promoting/celebrating events throughout the metropolitan area.

Rationale – A diverse working group of community organizations will establish awareness of Alzheimer’s disease and other related diseases across populations within the District of Columbia through events that bring populations together and highlight the disease.

Responsible Parties – D.C. Office on Aging, D.C. Department of Health, D.C. Department on Disability Services, D.C. Department of Veteran Affairs, AARP, Faith-Based Organizations, Limited English Proficiency (LEP) Organizations, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

11. Disseminate appropriate content to populations within the District of Columbia by developing print, radio, television, and online campaigns that raise the awareness of Alzheimer’s disease and other related diseases.

Rationale – Enlisting the support of various media sources will improve community understanding of issues related to Alzheimer’s disease and other related diseases. Disseminating accurate, relevant, and relatable information is essential to increasing public awareness and knowledge of societal issues. Increased access to information will reduce public stigma and improve proactive behavior relating to health and overall wellness.

Responsible Parties – D.C. Office on Aging, Health Care Providers, National Bureau of Statistics Center for Disease Prevention, U.S. Census Bureau, American Community Survey, Senior Wellness Centers, AARP, D.C. Department of Health, D.C. Department and Human Services, Broadcast Companies, Local Radio Stations, Print/Online Publications, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

12. Disseminate educational materials to diverse populations by applying appropriate literacy, language, and legibility standards of the District of Columbia.

Rationale – Disseminating information to diverse populations requires the development of comprehensible educational materials in an array of languages and literacy levels. In order to effectively reach all community members, materials designed to increase awareness and knowledge must provide information that is easily understood by the target audience. This strategy will enhance the opportunity for improved knowledge and understanding, regardless of factors associated with race, educational level, and socioeconomic status.

Responsible Parties – D.C. Office on Aging, Health Care Providers, National Bureau of Statistics Center for Disease Prevention, U.S. Census Bureau, American Community Survey, Senior Wellness Centers, AARP, D.C. Department of Health, D.C. Department and Human Services, Broadcast Companies, Local Radio Stations, Print/Online Publications, Faith Based Organizations, Community Centers, Community Advocates, Housing Community, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

Long Term

13. Partner with organizations currently addressing members of the population with a higher prevalence of hypertension, heart disease, diabetes, and obesity; and educate these individuals on the correlation between adverse health conditions and Alzheimer’s disease and other related diseases.

Rationale – Based on findings from the American Heart Association, American Stroke Association, and the Alzheimer’s Association, a healthy heart is interrelated to a healthy brain. Populations with an increased presence or predisposition of hypertension, heart disease, diabetes, and obesity are therefore at greater risk of developing Alzheimer’s disease and other related diseases among its members. Controlling the disease or bringing it to complete abatement requires education on the causes as well as the prevention.

Responsible Parties – Health Clinics, Health Care Providers, National Institute of Health, Mental Health Professionals, Medical Professionals, Local/Federal Human Resources Departments, Limited English Proficiency (LEP) Organizations, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

14. Utilize media and social network sources to promote participation in clinical trials among populations marked by Alzheimer’s disease and other related diseases.

Rationale – The media and social networks are essential vehicles to disseminate information. Through these modes of communication, diverse populations can be informed about the purpose of a clinical trial, how they will benefit from participation, what the eligibility criteria are, and the rights of participants. They will also have access to local health/medical-related institutions where clinical trials are being conducted that specifically pertain to Alzheimer’s related diseases.

Responsible Parties – Health Clinics, Health Care Providers, National Institutes of Health, Mental Health Professionals, Medical Professionals, Local/Federal Human Resources Departments, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

15. Improve intergenerational participation through established partnerships with schools interested in administering poster/essay contests emphasizing the social impact of Alzheimer’s disease and other related diseases.

Rationale – Teenagers and young adults interested in understanding or researching Alzheimer’s disease and other related diseases will be encouraged to learn more about the disease through contests and competitions that speak to a youth’s perspective of the disease. Teenagers whose family members are affected by Alzheimer’s disease and other related diseases and people experiencing onset of the disease will also be encouraged to participate. The ultimate goal is to increase knowledge of Alzheimer’s disease and other related diseases among youth in the District of Columbia and enhance their career interests.

Responsible Parties – D.C. Office on Aging, D.C. Public Schools, D.C. Charter Schools, Commission on Aging, Alzheimer’s Foundation of America Teens (AFA Teens), National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

Training and Workforce Development

Short Term

1. Establish a certification to enhance training requirements including a competency component about Alzheimer’s disease and other related diseases for clinical/licensed professionals, direct care providers, state agency staff, first responders, caregivers, guardians, and conservators.

Rationale - Enhancing training requirements will increase competency among direct care employees on how to provide quality care to persons with Alzheimer’s disease and other related diseases.

Responsible Parties - Boards of Social Work, Medical Professionals, Nurses, Mental Health Professionals, Health Professional Licensing Association, U.S. Department of Health and Human Services, EMS, MPD, Nursing Homes, Assisted Living Facilities, D.C. Superior Court, Shelters, Adult Day Care Centers, Group Homes, AARP, Legal Counsel for the Elderly, Office of Health Care Ombudsman, D.C. Department of Health, D.C. Department of Behavioral Health, Home Health Care Agencies (EPD waiver providers), D.C. Department of Health Care Finance, National Alzheimer’s Association, Alzheimer’s Association National Capital Area Chapter, and other appropriate organizations & institutions

Mid Term

2. Collaborate with government agencies and community partners to provide workforce training and assist in planning the Dementia/Alzheimer's Symposium for professionals. The citywide symposium will provide information on current research, promising practices, and pertinent issues related to the care of individuals with Alzheimer's disease and other related diseases as well as their caregivers.

Rationale - Planning an Alzheimer's/Dementia Symposium will increase knowledge on Alzheimer's disease care best practices and important issues related to Alzheimer's disease and other related diseases.

Responsible Parties - U.S. Department of Health and Human Services, MPD, D.C. Fire and EMS Department, Nursing Homes, Assisted Living Facilities, D.C. Superior Court, Shelters, Adult Day Care Center, Group Homes, AARP, Legal Counsel for the Elderly, Office of Health Care Ombudsman, D.C. Department of Health, D.C. Department of Behavioral Health, D.C. Office on Aging, Boards of Social Work, Medicine, Nursing, and Psychology; Health Professional Licensing Association, U.S. Department of Health and Human Services, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions

Long Term

3. Establish partnerships with institutions of higher education (IHEs) to increase the network of Alzheimer's disease care specialists by including training in post-graduate Alzheimer's disease programs for nursing, medicine, psychiatry, neurology, psychology, social work, pharmacy, gerontology, and related disciplines.

Rationale - It is critical that partnerships be developed with local institutions of higher education to enhance the knowledge base of Alzheimer's disease care specialists serving the population.

Responsible Parties - Providence Hospital, Washington Hospital Center, George Washington Hospital, Georgetown University Hospital, Howard University Hospital, American University, Georgetown University, Howard University, George Washington University, University of the District of Columbia, Gallaudet University, Catholic University, National Alzheimer's Association, Alzheimer's Association National Capital Area Chapter, and other appropriate organizations & institutions



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GLOSSARY

Alzheimer's Disease - Alzheimer's disease is the most common form of dementia, a general term for memory loss and other intellectual abilities serious enough to interfere with daily life. Alzheimer's disease accounts for 50 to 80 percent of dementia cases.

Caregiver – Refers to anyone who provides assistance to someone else who is in some degree incapacitated and unable to completely care for themselves.

Conservator – a guardian and protector appointed by a judge to protect and manage the financial affairs and/or the person's daily life due to physical or mental limitations or old age.

Dementia – Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.

EPD Waiver Program - The EPD waiver program is a choice program for the elderly and individuals with physical disabilities who are able to safely receive supportive services in a home and community-based setting. The beneficiary or authorized representative can choose a provider of services from the approved directory.

First Responder – is a person who has completed a course and received certification in providing pre-hospital care for medical emergencies. They have more skill than someone who is trained in basic first aid, but they are not a substitute for advanced medical care rendered by emergency medical technicians (EMTs), emergency physicians, nurses, or paramedics.

Guardian – is a person who has the legal authority (and the corresponding duty) to care for the personal and property interests of another person, called a ward. Usually, a person has the status of guardian because the ward is incapable of caring for his or her own interests due to infancy, incapacity, or disability.

Hospice – Gives supportive care to people in the final phase of a terminal illness aiding them in focusing on comfort and quality of life. The goal is to allow patients to be as comfortable and pain free as possible, so that they can live each day as fully as possible. Hospices are designed to provide support for the patients' medical, emotional, social, and spiritual needs.

Long-Term Care Ombudsman – Long-Term Care Ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities. They work to resolve problems of individual residents and to bring about changes at the local, state, and national levels that will improve residents' care and quality of life.

Medicaid – is the United States health program for families and individuals with low income and resources.

Medicare – is a national social insurance program, administered by the U.S. federal government since 1965, that guarantees access to health insurance for Americans aged 65 and older and younger people with disabilities as well as people with end stage renal disease (Medicare.gov, 2012) and persons with Lou Gehrig’s disease.

Power of Attorney – is a written authorization to represent or act on another’s behalf in private affairs, business, or some other legal matter. The person authorizing the other to act is the principal, grantor, or donor (of the power). The one authorized to act is the agent or attorney or, in some common law jurisdictions, the attorney-in-fact.

Respite Care – is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home.

RESOURCES

A.D.E.A.R Alzheimer's Disease Education & Referral Center (800) 438-4380

PO Box 8250
Silver Spring, MD 20907

Alzheimer's Association (800) 272-3900

225 N. Michigan Ave., Fl. 17
Chicago, IL 60601
<http://www.alz.org/>

Alzheimer's Foundation of America (AFA) (866) 232-8484

322 Eighth Ave., 7th Floor
New York, NY 10001
www.alfdn.org

Center for Medicare & Medicaid Services (800) 267-2323

7500 Security Blvd.
Baltimore, MD 21244
www.cms.hhs.gov

D.C. Office on Aging Information & Assistance (202) 724-5626

500 K St., NE
Washington, DC 20002
www.dcoa.dc.gov

Employee Benefits Services Administration, U.S. Department of Labor (866) 563-3278

200 Constitution Ave., NW Room 5625
Washington, DC 20210
www.dol.gov/ebsa

FDA for Older Persons (888) 463-6332

5600 Fishers Ln.
Rockville, MD 20857
www.fda.gov/oc/seniors

Forest Side (866) 965-2891

2701 Military Rd., NW
Washington, DC 20015
Services: Alzheimer's Care

Grand Oaks (888) 619-7742

5901 Macarthur Blvd., NW

Washington, DC 20016

Services: Assisted Living, Short Term Care: Rehabilitation, Respite, Alzheimer's Care, and Hospice

Health Resources & Services Administration (888) 275-4772

5600 Fisher Ln.

Rockville, MD 20857

www.hrsa.gov

Knollwood Military Retirement Community (866) 379-8263

6200 Oregon Ave., NW

Washington, DC 20015

Accepts Medicare/Medicaid

Services: Nursing Home, Alzheimer's Care, Assisted Living, Continued Care Community, and Senior Community

Methodist Home (877) 306-0051

4901 Connecticut Ave., NW

Washington, DC 20008

Accepts Medicare/Medicaid

Services: Nursing Home, Alzheimer's Care, Assisted Living, and Senior Community

National Council on Aging (800) 677-1116

1901 L St., NW, 4th Floor

Washington, DC 20036

<http://www.ncoa.org/>

National Institute on Aging (800) 222-2225

31 Center Drive, MSC 2292 Building 31, Room 5C27

Bethesda, MD 20892

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

P&B Rest Haven Inc (888) 268-0517

1221 Gallatin St., NW

Washington, DC 20011

Accepts Medicare/Medicaid

Services: Assisted Living, Micro-Community: Residential Care Facility, and Alzheimer's Care

U.S. Administration of Aging (202) 619-0724

One Massachusetts Ave., NW

Washington, DC 20001

www.aoa.gov

USDA Food and Nutrition Service (703) 305-2052

3101 Park Center Dr., Room 926
Alexandria, VA 22302
www.fns.usda.gov

U.S. Department of Health & Human Services (877) 696-6775

200 Independence Ave., SW
Washington, DC 20201
www.hhs.gov

U.S. Department of Veteran Affairs (800) 827-1000

801 Vermont Ave., NW
Washington, DC 20420
www.va.gov

U.S. Senate Special Committee on Aging (202) 224-5364

G31 Dirksen Senate Office Building
Washington, DC 20510
www.aging.senate.gov

U.S. Social Security Administration (800) 772-1213

6401 Security Blvd.
Baltimore, MD 21235
www.ssa.gov





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