



*December, 2013*

# **HAWAII 2025:** State Plan on Alzheimer's Disease & Related Dementias

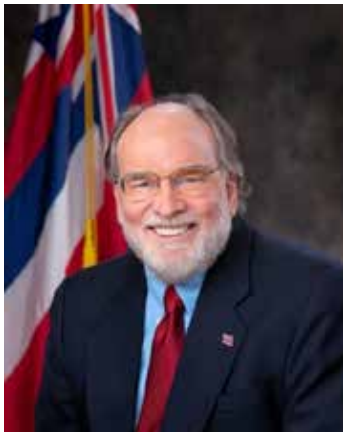


Executive Office on Aging  
Department of Health



## *Special Message from Governor Neil Abercrombie*

### **In Recognition of the Hawai'i 2025 State Plan on Alzheimer's Disease**



We are proud to present the *Hawai'i 2025: State Plan on Alzheimer's Disease and Related Dementias*. This report is the result of hard work by state experts, healthcare professionals and community stakeholders who are dedicated to improving the quality of life for those afflicted with dementia and their caregivers.

Dementia is considered a global public health crisis and affects more than 27,000 people in Hawai'i. Due to our rapidly aging population, this figure is anticipated to increase by 48 percent by 2025.

The most important known risk factor for Alzheimer's disease is age, and almost half of individuals 85 years and above have cognitive impairment. Life expectancy in the *Aloha* State is the highest in the nation, but this comes with the realities of an elderly growth rate which exceeded the national average in 2000. In 2030, 22 percent of our population will be age 65 and over.

We are aiming high for the first goal of the National Plan to Address Alzheimer's Disease, which is to prevent and effectively treat Alzheimer's disease by 2025.

We must increase funding for global and national research so that one day, we can live in a world without the threat and heartbreak of this disease.

*Aloha,*

**NEIL ABERCROMBIE**  
Governor, State of Hawai'i

**NEIL ABERCROMBIE**  
GOVERNOR OF HAWAII

**GARY L. GILL**  
ACTING DIRECTOR OF HEALTH



**WESLEY LUM, PH.D., MPH**  
DIRECTOR

Telephone  
(808) 586-0100

Fax  
(808) 586-0185

**STATE OF HAWAII**  
**EXECUTIVE OFFICE ON AGING**  
NO. 1 CAPITOL DISTRICT  
250 SOUTH HOTEL STREET, SUITE 406  
HONOLULU, HAWAII 96813-2831

Since the summer of 2011, a passionate group of community stakeholders have volunteered their time to identify challenges and barriers and seek solutions for the growing threat of Alzheimer's disease and related dementias in our islands.

The Hawaii Executive Office on Aging has provided staff support and coordination, and will continue to prioritize the implementation of Hawaii's first plan. This is a living document that will be updated annually. Going forward, we will seek the feedback of the public and those living with dementia, and build a committed and powerful Hawaii dementia coalition.

We are grateful for all the hours of group work, and the expertise and wisdom of the key informants and content experts who contributed to this plan. We also honor and align with the National Plan to Address Alzheimer's Disease, which is an inspiration to us all.

This disease touches the lives of so many that it's really a community responsibility to make our infrastructure, healthcare systems, and neighborhoods dementia capable and dementia friendly. In 2012, Hawaii had approximately 64,000 dementia caregivers, delivering 73 million hours of unpaid care. They deserve our support and recognition.

We must increase early and accurate diagnosis of dementia, support research efforts, improve treatment after diagnosis, support our family caregivers, improve healthcare delivery systems, expand access to crucial home and community based services, and provide housing, financial and legal services that are affordable and accessible to all. Facing these challenges will require hard work and effective collaboration across all sectors of our state.

We dedicate this plan to all those who have been and will be touched by dementia.

Thank you,

Wesley Lum, PhD, MPH  
Director



Frances and Matsue Kakugawa

*"If I could speak, this is what  
My voice would say:  
Do not let this thief scare you away.  
Do not let this thief intimidate you  
Into thinking I am no longer here...  
  
My words have all forsaken me,  
My thoughts are all gone.  
But do not let this thief  
Forsake you from me.  
Speak to me for I am still here.  
I understand hugs and smiles  
And loving kindness.  
Speak to me and not around me.  
I am not she or he or even a room number...  
  
Yes, I am still here.  
Help me keep my dignity.  
Help me remain a human being...  
In my world of silence.  
I am still here.  
Oh, I am still here."*

*- Frances Kakugawa, 2002, pp. 31-32*

*We are committed to embrace and  
support with Aloha, all of Hawaii's people  
who are touched by  
Alzheimer's Disease and Related Dementias –  
from early detection to end of life –  
always keeping alive the hope of prevention and  
eventual cure, and aiming for  
the best quality of life for all.*

## INTRODUCTION

When Kailua residents Mark Olds and his wife, Clara, sought medical attention for a speech problem she had been experiencing, she underwent a battery of neurological tests and was diagnosed to be suffering from a speech impediment, for which she was referred to speech therapy. However, her condition continued to worsen. A year and a half and a fourth neurologist later, they learned Clara was suffering from early-onset Alzheimer's disease.

Mark cared for Clara for eight years. According to Mark, he "felt so powerless and helpless in watching her deteriorate. I used to just curse this illness," he says. "I just prayed for the strength to get me through one day at a time. And I cried almost every day. Once, maybe, I went four days without crying." Shaking his head, he says, "It took a lot out of me." Their caregivers became an indispensable part of the family, but Mark was disappointed that "people who I thought would be there for Clara weren't!" But, he "held on to a sense of equilibrium by paddling, running and doing simple errands during weekly periods of respite care."

Mark's experience highlights the social, economic, and emotional costs of Alzheimer's disease. Each test Clara needed added to the cost. So did the respite care he received that helped him through the eight years of caring for his wife.

The year and a half it took before they finally got the correct diagnosis was time denied planning for Clara's final years. Because he followed through on his promise to Clara to care for her at home, there was no nursing home cost that others face. Though physically and emotionally taxing, learning to care for Clara through the final stages of her life became a calling for Mark – a way to honor their 30 years of marriage, and a way to let his wife know he loved her to the end. When asked if he would make the same choices, "I would," he says firmly. "I took care of her with lots of love, the best I could. I took care of her." (Condensed from Tani, 2013.)

With the numbers of Hawaii residents 65 years and older expected to surge in the next decade, Mark's and Clara's experience may be shared by many more residents of Hawaii unless changes can be made in diagnosing, treating, and caring for individuals with Alzheimer's disease and related dementias (ADRD) and their families.

The *Hawaii 2025: State Plan on Alzheimer Disease and Related Dementias* is a blueprint created to greatly improve the way individuals with ADRD and their families will live in their communities and be served by its institutions. The plan is the culmination of recommendations and discussions from (1) seven workgroups of the Hawaii ADRD Task Force, (2) caregiver and key informant surveys conducted in Hawaii, (3) interviews with Hawaii experts and leaders, and (4) the recommendations of the National Plan to Address Alzheimer's Disease, which was released in May, 2012.



*Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias*

# TABLE OF CONTENTS

<b>Introduction</b>	<b>4</b>
<b>I: Background</b>	<b>6</b>
<b>II: Methodology</b>	<b>15</b>
<b>III: Recommendations</b>	<b>16</b>
<b>IV: Next Steps: Discussion</b>	<b>30</b>
<b>V: Acknowledgements, Hawaii Resources, Useful Links</b>	<b>33</b>
<b>Appendices</b>	<b>40</b>

## FREQUENTLY USED ACRONYMS & ABBREVIATIONS

<b>AD</b>	Alzheimer's Disease	<b>EOA</b>	Executive Office on Aging
<b>ADRC</b>	Aging and Disability Resource Center	<b>JABSOM</b>	John A. Burns School of Medicine, University of Hawaii
<b>ADRD</b>	Alzheimer's Disease and Related Dementias	<b>LTSS</b>	Long-Term Services and Supports
<b>ACA</b>	Affordable Care Act	<b>MCI</b>	Mild Cognitive Impairment
<b>BRFSS</b>	Behavioral Risk Factor Surveillance Survey	<b>NIH</b>	National Institutes of Health
<b>CDC</b>	United States Centers for Disease Control and Prevention	<b>POLST</b>	Physician Orders for Life Sustaining Treatment
<b>CMS</b>	Centers for Medicare and Medicaid Services	<b>REACH</b>	Resources for Enhancing Alzheimer's Caregiver Health
<b>DHHS</b>	United States Department of Health and Human Services, National Institutes of Health		



# I. BACKGROUND

## Definition of Dementia and Prevalence

Dementia is the progressive decline of a person’s cognitive abilities of which Alzheimer’s disease is the most common type, accounting for approximately 60-80% of the dementia cases in the United States. As the disease progresses, functional abilities decline, resulting in an individual’s inability to carry out such basic bodily functions as walking and swallowing, which is ultimately fatal (Alzheimer’s Association, 2013).

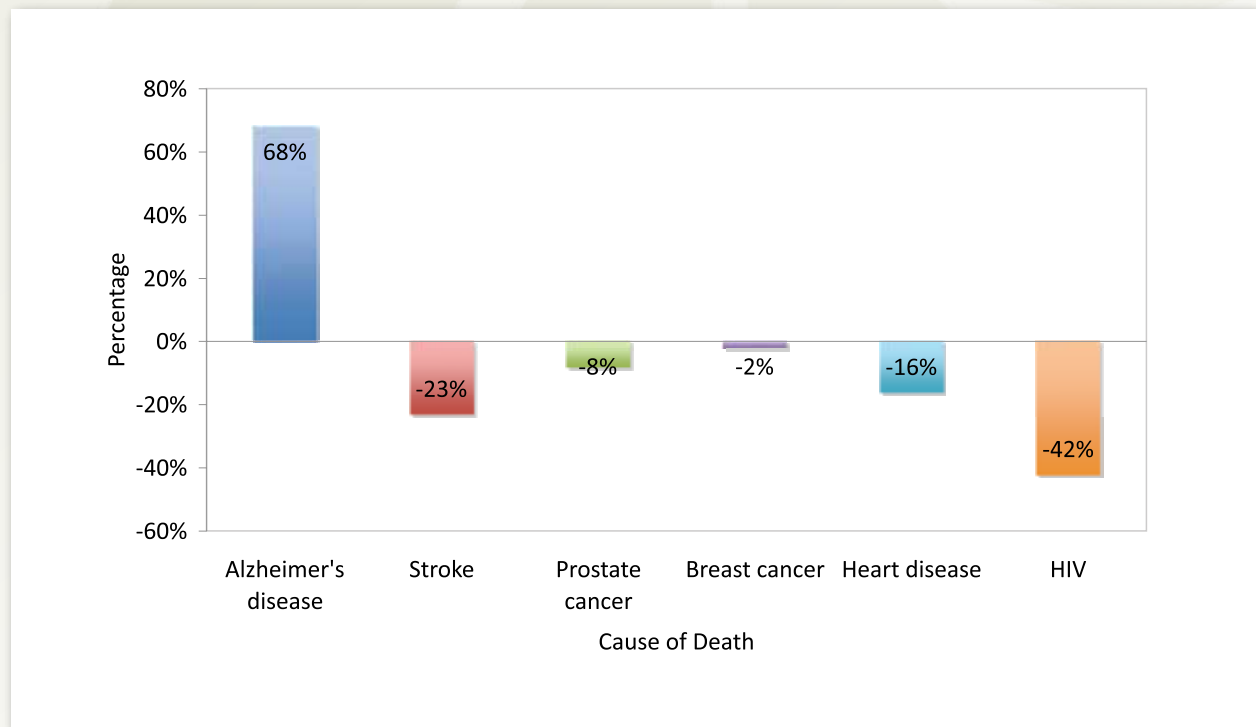
The 2013 Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), defines the clinical criteria that physicians use to identify the types of dementia. Definitions for the term dementia have changed in 2013 to Major and Mild Neurocognitive Disorder. However, the Hawaii State Plan on ADRD will use the term dementia.

Besides Alzheimer’s disease there are other causes of dementia: Vascular Dementia, Dementia with Lewy Bodies, Mixed Dementia, Parkinson’s disease, Frontotemporal Dementia, Creutzfeldt-Jakob disease, Normal Pressure Hydrocephalus, Huntington’s disease, and Wernicke-Korsakoff Syndrome (see Appendix A for types of dementia and their symptoms).

There are rare hereditary types of dementias, as well as alcoholic dementia, HIV-associated dementia, and “secondary dementias” that occur with other diseases like advanced Parkinson’s disease (U.S. Department of Health and Human Services (DHHS), 2013).

Alzheimer’s disease is the 6th leading cause of death in the U.S., and the only cause of death among the top 10 that cannot be prevented, cured or even slowed. As seen in Figure 1, while deaths from other major diseases have decreased (stroke, cancer, heart disease, HIV), deaths from Alzheimer’s are rising. Since 2000, deaths from Alzheimer’s disease have risen 68% (Alzheimer’s Association, 2013a). (See Appendix B for causes of death in Hawaii.)

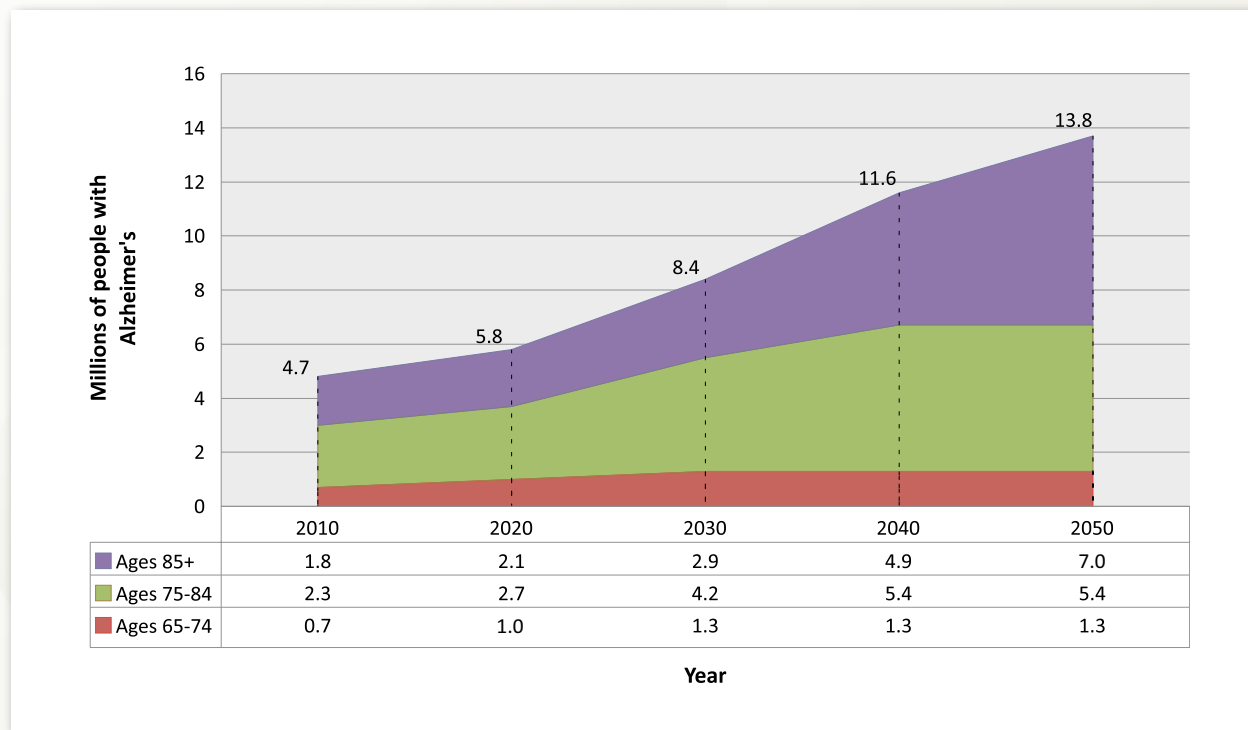
**Figure 1 - Percentage changes in selected causes of death in the U.S., 2000-2010 (all ages)**



Note. From 2013 Alzheimer's Disease Facts and Figures, by the Alzheimer's Association 2013a, p. 25.

In 2010, an estimated 4.7 million people 65+ in the United States were diagnosed with Alzheimer’s disease (Figure 2). By 2050, this number is expected to almost triple. Someone in the U.S. develops Alzheimer’s disease every 68 seconds (Alzheimer’s Association, 2013a). In 2013, more than 5 million Americans are living with the disease (Alzheimer’s Association, 2013a).

**Figure 2 - Projected number of people age 65 and older (total and by age group) in the U.S. population with Alzheimer’s disease 2010 to 2050**



Note. Adapted from 2013 Alzheimer’s Disease Facts and Figures, by the Alzheimer’s Association 2013a, p. 20.

In 2010, Hawaii had approximately 27,000 cases of diagnosed dementia for those age 65 and above. This number is expected to reach 34,000 by 2025, an increase of 48% (Alzheimer’s Association, 2013). These national and Hawaii estimates do not reflect a greater number of people who are undiagnosed. Boustani et al. (2003) estimated that approximately two-thirds of the people who meet the diagnostic criteria for ADRD have not received a diagnosis (as cited in Alzheimer’s Association & Centers for Disease Control and Prevention, (CDC), 2013).

New diagnostic criteria for Alzheimer’s disease were published by the National Institute on Aging (NIA) and the Alzheimer’s Association in 2011 and identified three stages of Alzheimer’s disease. “The three stages of Alzheimer’s disease are preclinical Alzheimer’s disease, mild cognitive impairment (MCI) due to Alzheimer’s disease, and dementia due to Alzheimer’s disease.” Scientific research has shown that Preclinical Alzheimer’s disease may start 10-20 years before symptoms occur (Alzheimer’s Association, 2013a).

“The field of aging and dementia is moving toward an earlier identification of clinical impairment, and the construct of mild cognitive impairment (MCI) has played a pivotal role. MCI is considered an intermediate state between the cognitive changes of aging and the earliest clinical features of dementia, particularly Alzheimer disease” (Petersen, et al., 2010, p. 889)

Those with MCI have only mild changes in memory that may not be noticed by anyone other than family or friends. The person is able to participate in normal activities, but may know there are cognitive changes. Having MCI is considered a risk factor for later development of dementia, but not everyone with MCI eventually develops dementia, and some improve if treatable conditions are identified, like medication side effects or depression (Alzheimer’s



Association, 2013c). A Mayo Clinic Study on Aging estimated that MCI is present in approximately 16% of the population of those 70 and over who do not have dementia, with a higher prevalence in men (Peterson et al., 2010).

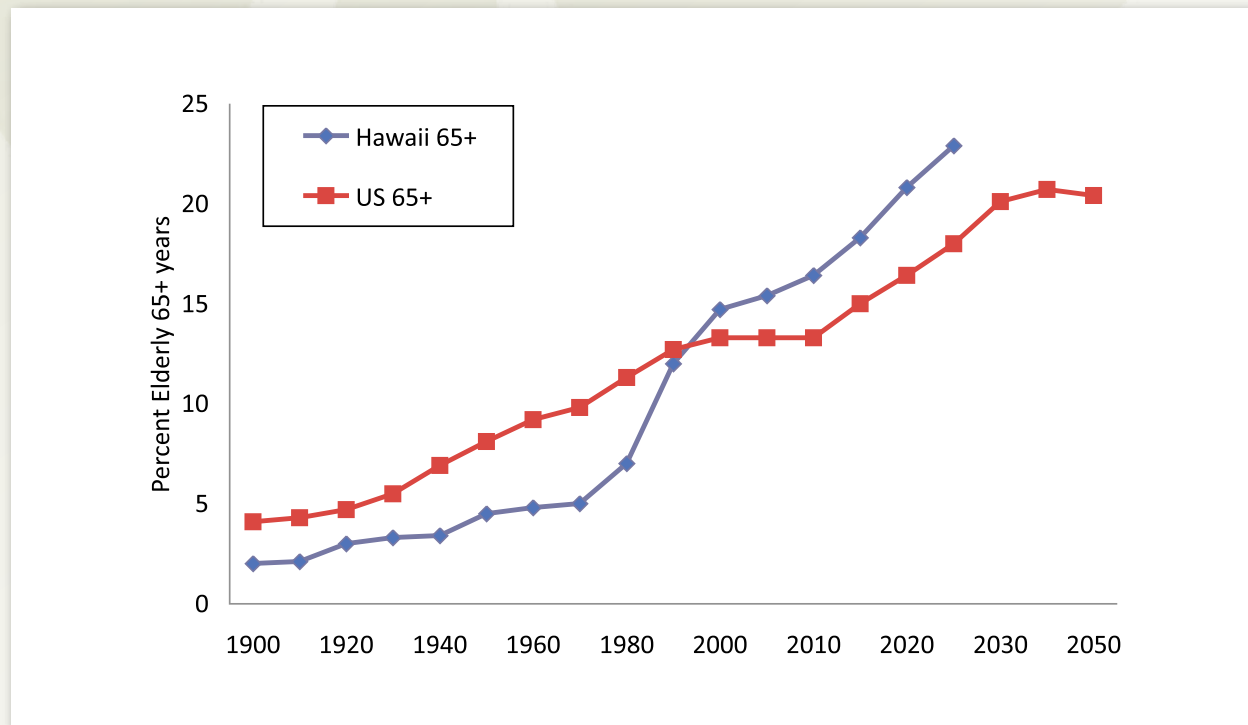
### Risk Factors

The most important known risk factor for Alzheimer’s disease is age. According to the Alzheimer’s Association, the likelihood of developing Alzheimer’s disease doubles about every five years after age 65; almost half of people over age 85 will have some form of memory loss. Other possible risk factors identified by scientists are family history, genetics, MCI, cardiovascular disease, fewer years of education, lack of social and cognitive engagement, traumatic brain injury, having Down Syndrome, or having Latino or African American heritage (Alzheimer’s Association, 2013a).

Due to the aging of the Hawaii population, the prevalence of age-related illness, including Alzheimer’s disease, is expected to increase. From 2010 to 2015, the Hawaii population over the age of 65 will increase by 67 percent.

As noted in Figure 3, Hawaii’s elderly growth rate (65 and over) surpassed the national average since the year 2000. Called “The Silver Tsunami,” the expected increase in the aging population is due to the Baby Boomer generation (born between 1946 and 1964), the first of whom reached age 65 in 2011. (See Appendix C for more information on Hawaii’s older adult population.)

**Figure 3 - Hawaii’s Elderly Growth Rate Compared to National Average (1900-2050)**



Note. From *Hawaii’s 2020 Vision: The State of Active Aging*, p. 2, by the Hawaii Department of Health and Kapiolani Community College, 2013, p.2.)

Furthermore, according to CDC (July 2013), Hawaii residents who were age 65 (between 2007 and 2009) had the highest average life expectancy in the nation – 86.3 years. Women in Hawaii had a higher average life expectancy at 88.2 years than men at 84.3 years.

Effective management of the following health behaviors may help to delay the progression of cognitive decline: controlling hypertension, diabetes, and depression; having a regular exercise routine, eating nutritional foods; and participating in mentally stimulating activities (Alzheimer’s Association, n.d.f). Based on recent studies, the Alzheimer’s Association now recommends the heart-healthy Mediterranean diet to help with memory and thinking, as well as other health conditions (Lourida, et al., 2013).

## ***Importance of Early and Accurate Diagnosis of Dementia***

Often, families and healthcare professionals are not aware that a person may have dementia because they are not familiar with the ten warning signs. A first step in raising awareness and increasing early and accurate diagnosis is to be familiar with them. There are ten early signs and symptoms of dementia: (1) memory loss that disrupts daily life; (2) challenges in planning or solving problems; (3) difficulty completing familiar tasks at home, at work, or at leisure; (4) confusion with time or place; (5) trouble understanding visual images and spatial relationships; (6) new problems with words in speaking or writing; (7) misplacing things and losing the ability to retrace steps; (8) decreased or poor judgment; (9) withdrawal from work or social activities; and (10) changes in mood and personality (Alzheimer's Association, 2013a. See Appendix D for list of warning signs).

Individuals who have one or more of the ten warning signs of dementia often resist seeking a clinical diagnosis because of lack of knowledge of the warning signs, shame, or a public perception that people with dementia cannot take part in ordinary activities or decision making. These misperceptions lead to delayed diagnosis until the disease has become moderate or severe.

Early diagnosis is important because it gives individuals with ADRD an opportunity to plan and make decisions about their own future while still lucid, prior to diminished mental capacity (Alzheimer's Disease International, 2011. See Appendix E for more reasons). Diagnosing dementia requires a medical evaluation, mental status testing, a physical and neurological exam, and tests to rule out other causes of dementia-like symptoms. Although a primary care physician can help screen for memory loss, once a screening indicates dementia, it is important to see a specialist like a neurologist or geriatrician for a more comprehensive assessment and treatment plan (Alzheimer's Association, 2013a). According to a University of Wisconsin study, an early diagnosis and treatment "could save millions or even billions of dollars while simultaneously improving care" (Weimer & Sager, 2009).

## ***Treatments for Dementia***

Treatments include both pharmacologic and non-pharmacologic therapies. There are no available medications that can stop the progression of Alzheimer's disease. Some prescribed drugs may reduce symptoms temporarily, but have mixed results with individuals. Most individuals

*Ken and Charlotte Takeya*



Ken has been the primary caregiver for his wife Charlotte for the last seven years. She was originally misdiagnosed with Alzheimer's disease. After six years, she was admitted to the hospital for an unrelated condition, where it was discovered that she did not have AD, but a form of dementia called normal pressure hydrocephalus. She has since had brain surgery and a shunt was inserted into her brain. She has shown improvement and can walk again with assistance, eat normal food and carry on a "normal" conversation. Unfortunately, her condition was not treated for six years, and she has lost most of her memory and her motor skills have diminished. Caring for her has been both a labor of love and an educational awakening.

Ken partners with her neurologist, educating people on the importance of correct diagnoses and the well-being of the patient and the caregiver. As a caregiver advocate he has learned there are many people who cannot afford a caregiving service and thus need help learning the correct caregiving skills: to not isolate, and to seek help when they need it.

with dementia also have multiple chronic conditions, complicating the management and treatment of those conditions (Alzheimer's Association, 2013a). Promising new drug therapies are being tested around the world and will require intensive clinical trials. A website is available through the Alzheimer's Association's TrialMatch® that gives more information about current Alzheimer's clinical trials.

Non-pharmacologic treatments may include proper approaches to managing behaviors and how to recognize triggers for behavioral issues, validation therapy, aromatherapy, and multisensory therapies like massage (Douglas, et al., 2004). None of these treatments, however, have been proven to change the course of the disease, but they may improve quality of life (Alzheimer's Association, n.d.e).

Alternative treatments also include herbal remedies, dietary supplements and certain foods that are being promoted to delay or prevent dementia. However, the Alzheimer's Association has concern about effectiveness and safety, purity of the products, allergic reactions, and drug interactions.

There are some preventable and treatable types of dementia. A meta-analysis by Clarfield (2003) of 39 published articles showed that nine percent of individuals experiencing dementia-like symptoms had potentially reversible forms of cognitive impairment upon proper workup (as cited in Alzheimer's Association & CDC, 2013).

### *The Stigma of Dementia*

Eliminating the stigma of dementia is one of the most important steps to improving the quality of life and care for people living with ADRD and their caregivers. According to a Marist Institute Poll, Alzheimer's disease was ranked the most feared diagnosis as reported by 44% of the respondents, while cancer was the second most feared (33%). (Home Instead Senior Care, 2013). Of those over 65, 56% named Alzheimer's disease as the illness they most wanted to avoid.

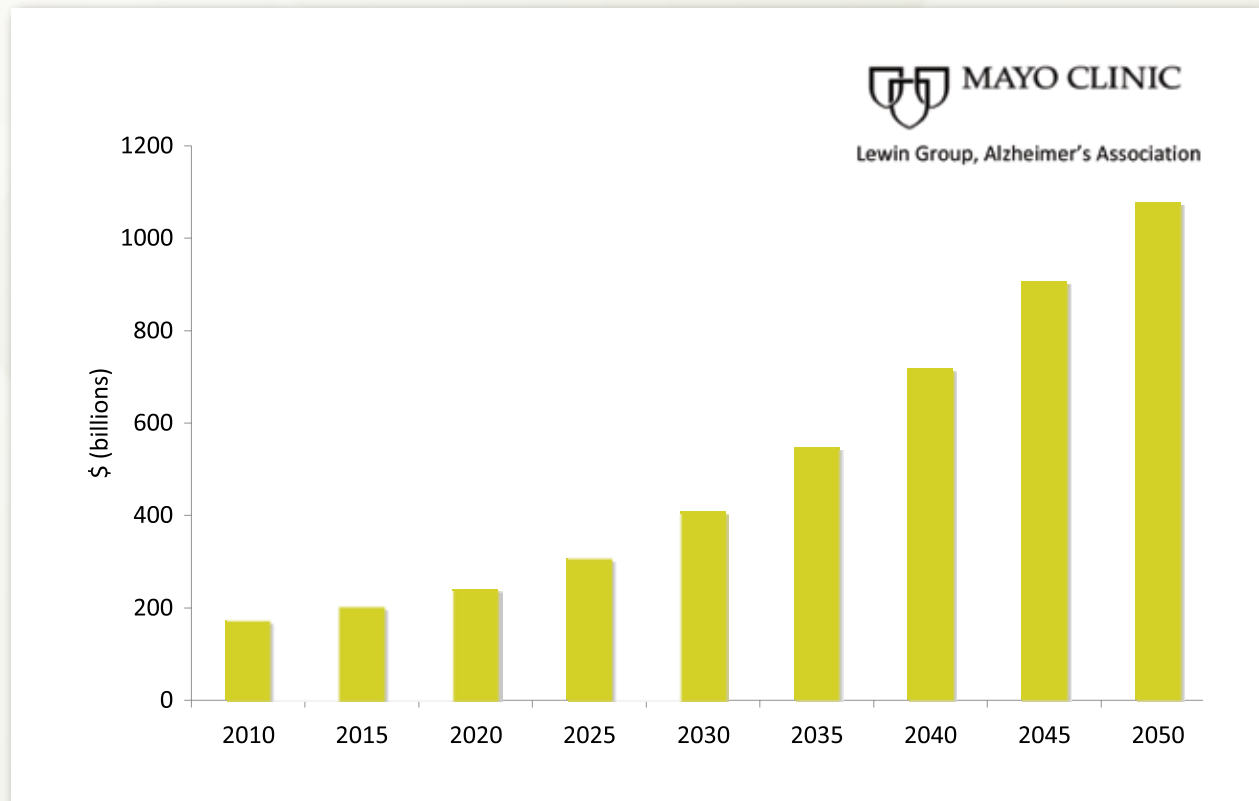
People living with dementia who are in the early stages, are particularly vulnerable to a society that does not understand, especially when there is early-onset (younger than age 65). Often, families, caregivers and individuals with memory loss feel isolated and stigmatized.

The public perception of Alzheimer's and dementia is often inaccurate. Because of this, people with dementia are misunderstood, undertreated, isolated or subject to ostracism, anger or impatience. Often, families or people with memory loss feel shameful. Public awareness and education are key in reducing stigma. People must know the ten warning signs of Alzheimer's disease, and how to make communities liveable for people with dementia and their caregivers.

### *The Cost of Dementia*

Figure 4 shows the rising cost of Alzheimer’s disease, with estimated figures from the Alzheimer’s Association and a Rand-funded study by Hurd and his colleagues (2013). The Hurd study estimated dementia to be among the most costly diseases in the nation. They estimated the 2010 cost for paid dementia care for persons 70 years and older was \$109 billion a year or \$28,501 per person (i.e., excluding co-morbidity and informal or unpaid care costs), a cost similar to heart disease and significantly higher than cancer. Hurd estimated that the total societal cost for dementia care was between \$159 and \$215 billion, depending on how informal costs are imputed. This amount will increase by nearly 80% by 2040 because of the aging of the population. The high cost of ADRD care is due to many factors, some of which are: higher nursing home costs and fewer long-term care beds; insufficient supply of geriatric health care workers; the role of informal caregivers in ADRD care. (See Appendix F for detailed estimates of dementia care.)

**Figure 4 - Cost of Alzheimer’s disease**

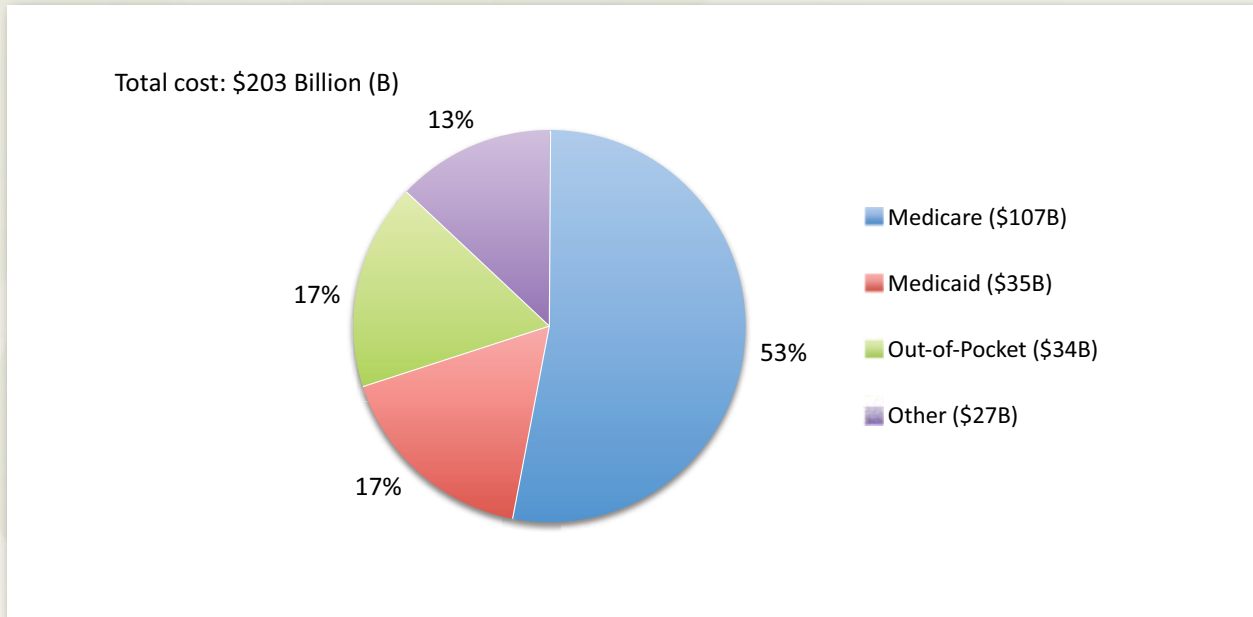


Adapted from Petersen (2013) with author’s permission.

Alzheimer's Association (2013a) facts (Figure 5):

- The average per person Medicare costs for those with ADRD are three times higher than those without ADRD
- The average per person Medicaid spending for seniors with ADRD is 19 times higher than for all other seniors
- Older people with Alzheimer's disease and other dementias have more hospital stays, skilled nursing facility stays and home health care visits than other older people.

**Figure 5 - Aggregate costs of care by payer for Americans age 65 and older with Alzheimer's disease and other dementias, 2013\***



\*Data are in 2013 dollars

Created from data from application of The Lewinn Model to data from the Medicare Current Beneficiary Survey for 2008. "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

Note. From 2013 Alzheimer's Disease Facts and Figures by the Alzheimer's Association (2013, March) Alzheimer's Association *Factsheet*, p.2.

Furthermore, people with Alzheimer's disease and other dementias have more than three times as many hospital stays per year as other older people. Older people with Alzheimer's disease and other dementias have more hospital stays, skilled nursing facility stays and home health care visits than other older people (Alzheimer's Association, 2013a).

Hawaii residents are faced with higher nursing home costs than their counterparts on the mainland. The annual median cost of a semi-private nursing home room in Hawaii in 2013 was \$127,568 compared to \$75,555 nationally (Genworth, 2012). According to AARP (2012), Hawaii had the fifth highest semi-private nursing home room rate in the nation in 2011. In addition, people with ADRD may be faced with even higher costs since approximately 20 percent of the nursing homes had higher rates for ADRD residents (MetLife, 2012).

The Alzheimer's Association (2013a) found that in 2009, 53 percent of nursing home residents in Hawaii had moderate or severe cognitive impairment, the third highest in the nation. An additional 22 percent had mild or very mild cognitive impairment.

Coupled with the high cost of nursing home care, there is a shortage of available long-term care beds in Hawaii. In 2010, Hawaii's nursing homes had a 92 percent occupancy rate, which is the 4th highest in the country. AARP (2012a) reported that in 2010, Hawaii was ranked 31 out of 51 (50 states and the District of Columbia) for number of assisted living and residential care units per 1,000 persons 65 years or older, and ranked 48 for number of nursing facility beds, exceeding only Alaska, Arizona, and Nevada.

### *The Role of Informal or Unpaid Dementia Caregivers*

Approximately 70% of dementia care is provided in the home setting. A large portion of the care for ADRD patients is being delivered through informal or unpaid caregivers, who provide care for a longer period of time than non-ADRD caregivers. The Alzheimer’s Association (2013a) reported that 43% of caregivers of persons with ADRD provided one to four years of care compared to 33% for non-ADRD caregivers. In Hawaii, a non-representative survey of dementia caregivers found that 38% had provided care for more than 60 months and 35% had provided care for 25 to 60 months. Sixty percent of the caregivers also reported that they provided at least 40 hours of care each week (Hawaii Dementia Caregiver Survey, 2013. See Appendix G for more results).

The valuable service that informal caregivers provide to their care partners with dementia often come with personal costs. For example, most of the respondents to Hawaii’s caregiver survey reported having at least one medical condition, with high blood pressure being the most frequently mentioned and being somewhat stressed (median of 7 on a 1 to 10 scale with 10 being high stress). Only slightly more than a quarter of the current (28%) and former (27%) caregivers reported having no medical conditions (Hawaii Dementia Caregiver Survey, 2013). The Alzheimer’s Association (2013a) estimated that in 2012, the toll of caring for an ADRD patient resulted in caregivers in Hawaii incurring a total of \$38 million (\$594 per caregiver) in additional health care costs per year. Family caregivers also often find themselves paying out-of-pocket to cover some of the expenses. Hawaii caregivers reported they paid a median of \$2,050 out-of-pocket each month for care recipients less than age 65 and \$300 for those 85 years or older (Hawaii Dementia Caregiver Survey, 2013).

### *Dementia, a Public Health Crisis*

The recent G8 Dementia Summit that took place in London in December, 2013 brought countries together to share and face the public health crisis. Dementia now affects more than 35 million people worldwide, expected to double every 20 years. In the G8 Summit Declaration, national and local responsibilities and commitments include: greater innovation to improve the lives of those with dementia and their caregivers; identification of a cure or therapy for dementia by 2025; increasing the amount of funding for dementia research and people involved in clinical trials; reduction of stigma, exclusion and fear of dementia; and, global collaboration on all priorities (United Kingdom Department of Health, 2013).

To think globally and act locally, what can Hawaii public health agencies and professionals do to meet this challenge and threat? More attention must be paid to addressing dementia’s impact not only for the individual but for the whole community.

Public health agencies and professionals can intervene by increasing data collection. Funded by the Alzheimer’s Association Aloha Chapter, the Hawaii Department of Health added the “Perceived Cognitive Impairment Module” to its annual Behavioral Risk Factor Surveillance Survey in 2011 (CDC, 2013). The cognitive module surveys self-reported confusion or memory loss among adults aged 60 or older. Highlights of the results showed that in Hawaii, 9% of those 60 and over report that they are experiencing confusion or memory loss that is happening more often or is getting worse. Nearly 90% of them have not talked to a health care professional about it – the highest among 22 states reporting data. (Alzheimer’s Association, n.d.b.) (See Appendices H and I for more information on cognitive impairment in Hawaii.)

Public health can intervene by promoting brain health by primary prevention, making the public aware of healthy behaviors like regular physical activity, attention to heart health and a healthy diet, not smoking, avoiding obesity,



“Productivity, independence, and quality of life for millions of Americans depend on the nation’s collective ability to prevent and treat cognitive impairment and dementia, and to promote cognitive functioning for individuals living in our communities. To accelerate efforts to meet these goals and help incorporate cognitive health in the plans and initiatives of states, territories, and communities in the U.S., we look forward to working with our partners to implement the actions identified in The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018.”

- Lynda A. Anderson, PhD, and Robert Egge  
Co-chairs of Leadership Committee  
(Alzheimer’s Association and CDC, 2013, p.5.)



and reduction of risk factors for dementia. Public health can also promote and assure early detection and diagnosis (Alzheimer’s Association, 2013b).

For the first time, Healthy People 2020 has included dementias in their 10-year public health improvement strategy. Their goal is to “reduce the morbidity and costs associated with, and maintain or enhance the quality of life for, persons with dementia, including Alzheimer’s disease” (DHHS, n.d.c). Additionally, the Alzheimer’s Association and CDC have launched “The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships.”

### ***The Patient Protection and Affordable Care Act (ACA) and Dementia***

With the Affordable Care Act, a new Medicare benefit for an annual wellness visit for every beneficiary includes screening for and detection of cognitive impairment. This benefit would increase the number of people who would get an earlier diagnosis, leading to more proactive measures before ADRD becomes moderate or severe. The ACA also mandates that nurse aides must be trained in dementia care and resident abuse prevention.

Electronic health records would benefit people with dementia, to assure that services or medications are not duplicated. These records would give doctors easier access to patients’ histories and also help with medication management.

There is also a Medicare pilot project that targets the senior population at high risk for hospital re-entry that will provide services. This project, created by Section 3026 of the ACA, includes people with cognitive impairment.

Those who have Early-Onset Alzheimer’s disease or dementia who are younger than 65, are no longer barred from some medical insurance plans for pre-existing conditions. There are also tax breaks or premium subsidies for low to moderate income individuals (Alzheimer’s Association, n.d.d).

Hawaii is in the process of creating the state model plan for ACA. There are some projects that would affect those with dementia in a positive way: a goal that 80% of Hawaii residents are assigned to a patient-centered medical home model of care by 2025; a pilot project “Community Paramedicine” will target rural areas by providing EMS personnel to visit residents who are frequent users of 9-1-1 or who need help; and a telehealth project that would offer consultation services with specialists, including geriatricians. (See Hawaii Healthcare Project in Useful Links, for more information on the Hawaii ACA model plan.)

## II. METHODOLOGY

*Hawaii 2025: State Plan on Alzheimer's Disease and Related Dementias* is a blueprint created to greatly improve the way individuals with ADRD and their families will live in and be served by their communities. The plan is the culmination of recommendations and discussions from (1) seven work groups of the Hawaii ADRD Task Force, (2) caregiver and key informant surveys conducted in Hawaii, (3) interviews with Hawaii experts and leaders, and (4) the recommendations from the National Plan to Address Alzheimer's Disease, which was released in May, 2012. The Hawaii plan is aligned with the National Plan goals and strategies.

President Obama signed the National Alzheimer's Project Act (NAPA) into law in January, 2011, which required the federal government to "create and maintain an integrated national plan to overcome Alzheimer's." The first national plan was released in May, 2012.

The national plan's intent is to partner with state plans, because it will take a combination of committed leadership and grass roots, community efforts to meet the present and future challenges of dementia.





### III. RECOMMENDATIONS

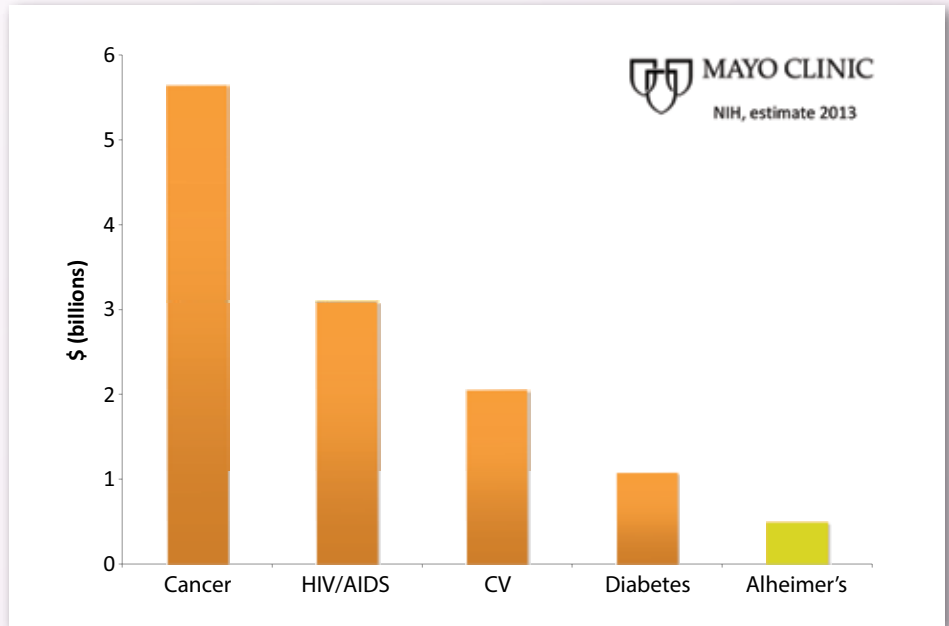
#### GOAL 1: Prevent and Effectively Treat Alzheimer’s Disease by 2025

Hawaii will seek to expand and support local research efforts, as well as keep Hawaii healthcare professionals and the public informed on the most current dementia research on effective prevention and treatment of dementia, both nationally and worldwide. Hawaii’s diverse cultural and ethnic environment can be a laboratory for studies unique to Hawaii, which could contribute to the growing worldwide body of research. Efforts will be made to examine the role culture plays in the perception and care of persons with ADRD.

Even though deaths from Alzheimer’s are increasing while deaths from other chronic diseases are decreasing (See Figure 1), research funding for Alzheimer’s disease is considerably lower than funding for other chronic diseases, as noted in Figure 6. Hawaii will encourage agencies and professionals to advocate on behalf of increased national funding for Alzheimer’s research so that Goal 1 becomes a reality.

**Strategy 1 - Develop a Hawaii research consortium to expand research and programs unique to Hawaii that have the potential to contribute to the science and understanding of ADRD worldwide.**

Figure 6 - NIH research investments




Note. Adapted from Petersen (2013) with author’s permission.

A Hawaii research consortium was established in 2013 to develop strategies to attract, grow and track research related to Alzheimer’s disease and related dementias in Hawaii and the Pacific Rim. A first step of the consortium will be to inventory past, present and planned cognition or dementia-related research programs in Hawaii, and to maintain and monitor a database of these projects. There will be an effort to encourage enrollment in Hawaii clinical trials through healthcare, aging and community networks. Also, there are opportunities for evidence-based studies involving Hawaii’s ethnically diverse community to explore lifestyles and cultural perceptions of dementia and caregiving.

The Honolulu-Asia Aging Study (HAAS) conducted from 1991 to 2012, and funded by the National Institutes of Health and the Alzheimer’s Association, was one of the first studies to show that untreated hypertension in middle life was associated with a significantly higher risk of developing dementia in later life for Japanese American men who participated in the study. However, if the hypertension was adequately treated, this increased risk was mitigated (Launer et al., 2000).

The HAAS data also demonstrated that higher physical activity like walking was associated with a lower risk of developing dementia over a 6-year follow-up period (Abbott et al., 2004).



**Strategy 2 - “Piggyback” on or build relationships with national research partners.**

Hawaii researchers will continue to seek partnerships with national organizations and universities in multi-center studies. Hawaii will follow the lead of the National Plan to Address Alzheimer’s Disease, which aims to increase enrollment in clinical trials and other clinical research through community, national, and international outreach.

**Strategy 3 - Convene an annual dementia care and research symposium with goals of fostering scientific collaboration and sharing of current dementia research with the Hawaii community.**

The symposium will feature national and Hawaii research and highlight local healthcare professionals, and will become an avenue for networking and collaboration about research priorities and progress. Another goal of the symposium will be to foster partnerships between the clinical (medical/healthcare) and service provider communities. These linkages are essential to providing the best possible dementia care.



“Increased enrollment in clinical trials is crucial for the development of better treatments and ultimately a cure for Alzheimer’s Disease. Participating in clinical trials and other research enables volunteers to access the latest experimental approaches available and provides them with care by clinical research staff” (DHHS, n.d.b. pp. 12-13).  
*- National Plan to Address Alzheimer’s Disease, Action 1.B.3*



The first Hawaii Dementia Symposium “Pathways to Excellence in Dementia Care & Research,” was held on February 8, 2012, attended by over 300 people, including physicians, allied health professionals, government agencies, non-profits, aging network professionals, and service providers. Keynote Speaker was M. Marsel Mesulam, MD, Director, Cognitive Neurology and Alzheimer’s Disease Center, Northwestern University.

**Strategy 4 - Share the latest information about promising research and interventions with Hawaii healthcare professionals, as well as the general public, through educational events, online sources, and the media.**

This information would include opportunities for clinical trial participation, any findings on pharmacological and non-pharmacological interventions, developments in effective treatments and prevention, reduction of risk factors, and brain health.

**GOAL 2: Enhance Care Quality and Efficiency**

In order for Hawaii to achieve the vision of the best quality of life for those touched by dementia, it is imperative to achieve the highest quality of culturally competent care possible and a state infrastructure sensitive to the needs of people with ADRD and their care partners. Quality care begins with “dementia capable” services. Consumers and their families need to have all appropriate services and care to maximize quality of life, delivered in a coordinated way from early and accurate diagnosis to the end of life.

**Strategy 1 - Be dementia capable.**

Being dementia capable must involve not only healthcare professionals and the direct care workforce, but also Hawaii’s aging and public health community. It means being culturally competent, to be able to communicate effectively and provide quality services for Hawaii’s many ethnic and cultural groups who are impacted by dementia. State agencies should work collaboratively to embed dementia capability in their plans.

As a first step, a statewide assessment will be conducted to determine how dementia capable Hawaii’s service systems are. These systems should include government agencies, healthcare practices and hospitals, service providers, first responders and law enforcement, public transportation, public housing, residential facilities, and the Hawaii Aging and Disability Resource Center (ADRC). Transportation, in particular, was identified by the Hawaii ADRD Task Force and key informants as having major barriers to adequate services for frail or cognitively impaired individuals, such as accessibility in rural areas, long wait times, affordability, and dementia capable staff.



Dementia capable services are tailored to the unique needs of persons with dementia and their caregivers. Dementia capable service systems:

- Identify those with dementia;
- Provide services using staff with dementia training;
- Communicate effectively with persons with dementia and their family caregivers; and
- Ensure that persons with dementia are supported in their decision-making about services and involve family caregivers when necessary.

- *Administration on Aging, Administration for Community Living. DHHS (n.d.a).*



“There is often overlap in what workers who come to a person’s home do for the person needing long term care services. I am looking forward to the ADRC to address overlapping services and identify gaps in services. The comprehensive assessment of the person and co-location of services, to the extent possible, will be a welcomed best practice.”

- *Suzanne Chun Oakland, Hawaii State Senator, Key Informant Survey*

**Strategy 2 - Create a one-stop resource for access to information and referral.**

The path to high-quality care and a dementia-capable community and infrastructure must also start with a one-stop resource for anyone needing help – a “no wrong door” for professionals and the general public that leads to effective options and advice. This is the vision of the ADRCs. The goal is for all of Hawaii’s ADRCs to be dementia capable and operating at full capacity.

Meanwhile, an interactive Hawaii dementia website will be created for anyone seeking dementia-related resources, links and information.



### **Strategy 3 - Build a workforce with the skills to provide high quality care for people with ADRD.**

There is a critical shortage of trained workforce professionals and paraprofessionals in Hawaii, a problem compounded in rural areas. The scarcity is worse in geriatric and gerontological specialties, and includes a need for geriatricians, geriatric psychiatrists, social workers, case managers, nurses, nurse's aides and other direct care providers, who are adequately trained in dementia care. (Hawaii Workforce Development Council, 2011)

A dementia capable workforce should also include providers of long-term services and supports and direct care workers in nursing homes and other residential care settings. The national movement to improve quality care in nursing homes has made progress in this area. The Centers for Medicare and Medicaid (CMS) created a training manual for nurse aides, Hand in Hand, a toolkit for person-centered care of persons with dementia. It's being used in some Hawaii skilled nursing facilities. This is to comply with an Affordable Care Act mandate that nurse aides receive annual training on dementia and how to prevent abuse.

Launched in 2012 by CMS, the National Partnership to Improve Dementia Care in Nursing Homes has been working with states to improve the quality of care for those with dementia living in nursing homes. One strategy is to reduce inappropriate use of anti-psychotic medications for behavioral issues, which have been shown to be dangerous and even deadly for dementia patients (Huybrechts, et al., 2012). Non-pharmacological approaches to dementia care are encouraged as an alternative, when appropriate. A recent 2013 CMS report shows that Hawaii ranks as the state with the lowest usage of nursing home antipsychotics in the nation (CMS, 2013).



The University of Hawaii John A. Burns School of Medicine Pacific Islands Geriatric Education Center conducts dementia-related trainings for allied health professionals and primary care physicians in Hawaii. JABSOM Department of Geriatrics has high national ratings and is one of the largest Geriatric fellowship programs in the country. Almost half of its graduated 157 geriatricians live and practice in Hawaii and the Pacific.

Kapiolani Community College's Kupuna Education Center has been doing its part to train and expand Hawaii's professional and paraprofessional workforce, train family caregivers, and promote active aging. Dementia curricula is included in all trainings. (see Hawaii Resources)



Practicing Hawaii healthcare professionals will be provided with continuing training on high quality standards and measures for dementia care. This will include primary care physicians, who should have a unified ADRD curriculum designed to enhance dementia screening, diagnosis and care skills for all stages of the disease.

There will be efforts to encourage and incentivize professionals and paraprofessionals to pursue careers in geriatric specialties, and attract more specialists to Hawaii. Possibilities for this include: student loan forgiveness and visas for foreign students; continuing education in geriatrics for current healthcare workers; examining barriers, such as low pay scales, for nurse’s aides and other healthcare workers.

**Strategy 4 - Ensure timely and accurate diagnosis.**

By 2025, primary healthcare providers will be fully engaged in dementia diagnosis and treatment, supported by a clear understanding and availability of care options. Every primary care physician will be trained in memory and dementia screening and will have access to referral resources. Quality of care for someone with dementia begins with an early and accurate diagnosis, but there are challenges to this in Hawaii and the rest of the world. “Among those living in the community, approximately two-thirds of the people who meet the diagnostic criteria for Alzheimer’s Disease or other dementias have not received a diagnosis” (Boustani, et al., 2003 as cited in Alzheimer’s Association & CDC, 2013).

Barriers include lack of public and professional awareness of the warning signs of dementia, or not communicating memory changes to the healthcare provider. Often misunderstood as normal aging or personality changes, dementia remains undiagnosed until symptoms are advanced.

The Affordable Care Act mandates coverage of a Medicare Annual Wellness Visit, which includes “detection of any cognitive impairment” during the visit.



“...to be an excellent dementia caregiver requires much more than what any basic training provides. It requires a loving and empathetic heart, extraordinary patience, and last but not least, a sense of humor...those intangible qualities that cannot be taught – a quick and easy smile, positive outlook, calming presence, and an awareness and intuition of the needs of the residents.”

- *Dorothy Colby, Administrator, Hale Kuike, Key Informant Survey*

“At the Kauai Dementia Clinic, many patients and families were relieved to discover that they were not dealing with Alzheimer’s, but another cause, frequently treatable and sometimes reversible.”

- *Humberto Blanco, Program Coordinator, Alzheimer’s Association, Kauai Office, Key Informant Survey*

Screening and assessment tools will be identified and made widely available in Hawaii’s clinical settings, including a road map on how to follow up if cognitive impairment is detected. An early diagnosis is still not enough. It has to be accurate, because approximately 9% of correctly diagnosed dementias can be reversed (Clarfield, 2003 as cited in Alzheimer’s Association & CDC, 2013). This will require training as well as access to referral resources. There are multiple reasons why an early diagnosis is important, including the ability to better plan for the future, to acquire the best medical management, to avoid or reduce costs, and plan for future needs (See Appendix E for more reasons).



**Strategy 5 - Educate and support people with ADRD and their families upon diagnosis.**

A major barrier for physicians and families upon first diagnosis of cognitive impairment or dementia is the lack of options for referrals for the interdisciplinary services that are necessary. An important first step is referral to the Alzheimer’s Association, Aloha Chapter branches in all counties (*See Hawaii Resources for a list of offices statewide*).

In order to link people with ADRD and their families to training and services, Hawaii’s physicians and health care providers will be trained on accessing long-term services and supports. An inventory of all dementia specific resources in Hawaii will be made accessible to the Hawaii healthcare community. Hawaii’s ADRCs will be dementia capable so that anyone needing information, referral or case management can find timely and effective help. Education and support should be culturally competent and target Hawaii’s different ethnicities, including Native Hawaiian and rural populations.

**Strategy 6 - Identify high-quality dementia care guidelines and measures across care settings.**

Hawaii will explore and identify the best existing and evolving dementia care guidelines and measures being used locally and nationally to adapt to the spectrum of Hawaii service providers and care settings, including primary care physicians, the direct care workforce, Hawaii’s aging and public health workforce, and caregivers. These trainings will include brain health, how to address behavioral issues, care for all stages of dementia, including issues specific to end-stage dementia, palliative care and hospice.

Dementia-specific, innovative models of care and best practices are being piloted and analyzed nationwide that show not only improved quality of care for people with dementia, but cost-savings as well. These include a team approach to dementia care, patient-centered approaches, and care tailored to the unique needs of the patient and care partners.



In a study at the Queen’s Medical Center researchers found an increase in the rate and overall number of visits by elderly patients (65 years or older) to the psychiatry emergency department (ED) from 2007 to 2010. Moreover, compared to younger age groups, elderly patients experienced a longer stay of over 6 hours, and those with dementia stayed over 9 hours. Many were admitted to the acute psychiatry ward often in an exhaustive but unsuccessful effort to find safe placement from the ED. (Lu et al., 2011) “These results reflect an acute shortage of mental health resources for Hawaii’s seniors, and such crises are expected to worsen given the steady increase of the elderly population. Given the very few number of geriatric psychiatry providers in Hawaii, we try to explore different models of enhancing care and access. These include educational opportunities for caregivers and primary care physicians, a consultation-based only clinic, partnership with long-term care facilities, and the use of telepsychiatry.”  
– Brett Lu, MD. PhD.

**Strategy 7 - Ensure that people with ADRD experience safe and effective transitions between care settings and systems.**

Being in unfamiliar environments is particularly hard on people with dementia and their caregivers. Any transition to a different setting can cause disruption and setbacks in stability, as well as posing physical and psychological risks. People with dementia are more prone to falls and have other chronic conditions that might require hospitalization or nursing home stays. Transitions occur between home, emergency room, hospital, skilled nursing facility, care home or foster home, assisted living, back and forth throughout the course of the disease.

“People with dementia have higher rates of emergency room visits and hospitalizations, two settings where they are vulnerable to stress, delirium, and unnecessary complications.” (DHHS, n.d.b. p. 23)  
- *National Plan to Address Alzheimer’s Disease, Strategy 2F*

It will be important to identify, expand, and put into practice models of hospital safety and care transitions for people with cognitive impairment, as well as research and pilot programs on avoiding unnecessary hospital readmissions and emergency room use by people with ADRD. There are also ways to make healthcare environments more friendly and adapted for those with cognitive impairment.

One of the major gaps that the ADRD Task Force and content advisors identified is that Hawaii lacks adequate capacity to handle an increasing number of behavioral crises that occur in patients with dementia. A special workgroup will be established to find ways to identify barriers, increase training and capacity in geriatric psychiatric and crisis services statewide.

**Strategy 8 - Advance coordinated and integrated health and long-term services and supports for individuals living with ADRD.**

There is a need to clearly map out coordinated care options for early, moderate, advanced and end of life stages and make them accessible to healthcare professionals and the public.

Care coordination and a team approach to dementia care has been shown to improve outcomes and reduce costs. Families trying to navigate the systems alone find it immensely challenging, even for those knowledgeable in healthcare. Often, care is fragmented, there is no record of all the medications prescribed, no case management, no supervision of consistent care.

Hawaii will expand and develop Memory Clinics so that all Hawaii residents with cognitive impairment will have access to the full range of interdisciplinary, coordinated care from diagnosis through the course of the disease in different settings, including community health centers, hospitals and private practices.



Kokua Kalihi Valley Comprehensive Family Services offers a monthly Memory Clinic that promotes collaborative assessment, evaluation, and treatment of dementia using a multidisciplinary team approach. Patients and caregivers are provided with education, support and follow up. The interdisciplinary team includes a geriatrician, psychiatrist, gerontologist, lawyer, registered dietician, and interpreter. The Memory Clinic has community partnerships with the University of Hawaii and the Alzheimer’s Association, Aloha Chapter.

**Strategy 9 - Improve care for populations in Hawaii who are disproportionately affected by ADRD, and for populations facing care challenges.**

These special populations include those with Down Syndrome, traumatic brain injury, homeless and those living in poverty with dementia, residents of rural areas, those with early onset dementia, and different ethnic groups.

This will require collaboration with Hawaii Down Syndrome advocates to better assist this population, who have a higher rate of dementia as they age. More than 75% of people with Down Syndrome 65 years and older have Alzheimer’s disease (Alzheimer’s Association, n.d.c).

People with early-onset Alzheimer’s disease or traumatic brain injury have additional challenges in the Hawaii community, not covered adequately by the aging network or adult mental health services.



“My husband was diagnosed with early-onset Alzheimer’s disease (EOAD) while he was in the prime of his career and personal life, when he was only 55 years old. We have two children, and this disease has taken a lot from our entire family. Now at age 60, he’s in the later stages of the disease. After struggling with memory loss for many years and seeing numerous doctors and finally taking a PET scan, only then was a diagnosis given. As his sole caregiver for over four years, I realized that in Hawaii we have a shortage or lack of services for people who are afflicted with EOAD. While Mike was in the early stages of AD, we desperately wanted him to attend a support group but were told that no such group existed on Oahu. I attended a wonderful Alzheimer’s Association training for caregivers that helped me so very much, but my only wish was that he too could have a support group to attend. As EOAD progresses, behavioral issues become apparent, often with agitation and violent random outbursts. This can be very stressful for the caregivers as well as for the afflicted person. It is vitally important to have a geriatric psychiatrist do an assessment. Mike was very fortunate to have a great geri-psych specialist who helped him tremendously. Finding placement at a qualified care facility can be quite daunting, especially



*Mike and Cindy Goya*

when one is so young and still able to walk, pace and wander. We do not have enough care facilities in Hawaii, especially ones that are specialized in Alzheimer’s disease and who are able to accommodate patients that have behavioral issues. We are in desperate need for more specialized services and care facilities that cater to the people who live with dementia and Alzheimer’s disease.”

*- Cindy Goya, family caregiver*



## GOAL 3: Expand Supports for People with Alzheimer’s Disease and Their Families

Quality, professional healthcare for people with dementia should be balanced with community supports necessary to help caregivers and families coping with the disease. Upon diagnosis, there should be easy and affordable access to a multitude of services and trainings, including respite, legal and financial counseling, advance care planning, and safety measures.

Seventy percent of Alzheimer’s care is provided in the home environment by unpaid or “informal” caregivers (Alzheimer’s Association, 2013a). In 2012, there were 64,000 documented self-identified Alzheimer’s/dementia family caregivers in Hawaii, delivering 73 million hours of unpaid care, at a total value of \$895 million. Many caregivers don’t self-identify, so this could be a conservative figure. Unpaid or “informal” caregivers are the backbone of dementia care, and without their contributions, the economy could not afford or adequately support those with the disease.



“All those who participate in the lives of people with Alzheimer’s disease should know or learn that, despite changes and loss of abilities, people with Alzheimer’s disease are able to find pleasure and experience satisfaction. The disease does not remove a person’s ability to appreciate, respond to and experience feelings such as anger, fear, joy, love or sadness. It is very important that family members, caregivers and health care providers recognize an individual’s abilities, interests and life-long skills and use this knowledge to help maintain and enhance that person’s quality of life.”

– Susan Hunt, MHA, CEO Hawaii Island Beacon Community, Key Informant Survey

### Strategy 1 - Ensure that Hawaii care partners and families receive culturally sensitive education, training and support materials.

A major barrier to optimal dementia care in the home setting is that the family or primary caregiver is not aware of resources available to them. They may not reach out for help for various reasons, are not aware of caregiver trainings on dementia, and often are not even aware of the warning signs of dementia.

Hawaii must ensure that the public and those committed care partners are well-educated about dementia and brain health, risk factors, recognition of early signs of dementia, stages of dementia and behavioral issues, and are able to maintain good health practices and appropriately access resources when necessary.

Culturally sensitive materials and trainings will be identified and expanded, then distributed throughout the community. This should include health information technology found through on-line links and referrals, available not only from home computers but in community settings.

### Strategy 2 - Enable Hawaii’s family caregivers and families to continue to provide care while maintaining their own health and well-being.

Family, friends, or neighbors who accept the responsibility for caring for someone with Alzheimer’s disease face many challenges, including risks to their own mental and physical health.

Dementia care can be rewarding and a commitment of love, but it is also a difficult journey, especially for primary caregivers. The daily toll it takes often includes sleep deprivation, burnout, stress, possible family feuding and disagreements on care decisions, loss of work and benefits, and financial or legal challenges that can deplete savings and limit options for care.

Evidence-based dementia caregiver trainings have been recently available in Hawaii, free to caregivers and proven to reduce stress and increase coping skills.

1. *Resources for Enhancing Alzheimer's Caregiver Health (REACH II)* training is available through Child & Family Service Honolulu Gerontology Program. Hawaii was one of five states to receive a 3-year grant in 2013 from The Rosalynn Carter Institute for Caregiving.
2. *What's Next* training offered by the Alzheimer's Association, Aloha Chapter. Efforts will be made to expand trainings like these throughout the state (See Hawaii Resources).

According to the 155 respondents to the non-representative Hawaii Dementia Caregiver Survey, the seven services they needed most were home-based respite care; personal care services like bathing, dressing and toileting; information about Hawaii caregiver resources, services, tips; homemaker services like house cleaning, shopping and errands; transportation assistance; case management; day care or day health services outside the home (see Appendix G for survey results).

Recommended strategies for improving caregiver well-being in Hawaii include the use of peer mentors or coaches, more access to caregiver support groups, affordable transportation options especially in rural areas, and available and affordable respite services inside and outside the home. Adequate services and supports should be accessible to all, despite financial circumstances, language, and culture.



*Arman and Anita Trubitt*

"I have been one of ten very lucky participants in the Alzheimer's Association Aloha Chapter program entitled *What's Next:*

*Learning to Feel Better and Care Better, a Psycho-educational Program for Caregivers of a Family Member with Dementia Living at Home.*

The biggest appreciation of all goes to the remarkable people who all learned that we could

be open with one another about our feelings, our vulnerabilities, and that we could talk about absolutely anything, all of which resulted in such positive change as we have learned to take care of ourselves better before we could take better care of our loved ones."

- Anita Trubitt, MSW, LCSW, MEd  
family caregiver

Support for Hawaii's dementia caregivers will include collaboration with employers and the business community to offer assistance to their employees who are balancing work and caregiving.

**Strategy 3 - Assist individuals and families in planning for future care needs, taking into account the cost and impact of dementia, inclusive of all levels of financial status.**

Surveys by AARP Hawaii (AARP, 2012b) and the Hawaii Long-Term Care Commission (2012) found that the majority of middle-age adults are not planning or prepared for the high cost of long-term supports and services (LTSS) in Hawaii. Hawaii's costs for LTSS are among the highest in the nation (AARP, 2012a). To add to this startling fact, Alzheimer's is among the most expensive chronic diseases, and can last for many years (Hurd et al., 2013).

Being prepared for the high cost of LTSS is important for those of all income levels. Early diagnosis can assure that individuals who have not yet prepared can still take part in important financial decision-making while still lucid enough to do so.

To address this, there will be a public awareness campaign on financing LTSS, one of the recommendations of the

Hawaii Long-Term Care Commission. The ADRD State plan recommends annual summits that will feature national presenters on all the options for LTSS: private, public and innovative, like participant-directed services programs.

Public education should target how individuals and families can prepare for LTSS through personal investments, long-term care insurance, reverse mortgages, savings, and other strategies in combination.

The state will make a resource list of financial professionals, organizations and providers that can offer pro bono or affordable services for families impacted by ADRD.

Efforts will be made to improve how public funding can better serve and give better access to those with dementia and their caregivers. Those who are eligible for Medicaid need not only essential medical services but also other coordinated care options, services and support, financial and legal counseling, support groups, counseling, case management. These expanded services allow them to stay in the home setting longer, avoiding placement in nursing facilities. Many of these home services are presently not covered entirely under Medicaid and Medicare.

Dementia is presently not included as a criterion for services in the Hawaii Adult Mental Health Program or in Hawaii's Medicaid health home pilot program or State Plan Amendment, and therefore, the Hawaii plan recommends advocating for increasing access to expanded services for the dementia population on Medicaid.

Also, the Medicaid eligibility process could be more streamlined when helping those with dementia in crisis situations, to help Adult Protective Services or for those who are homeless, at risk, or financially challenged. Families, case managers and caregivers often must wait for weeks for needed assistance, during which time the person with dementia suffers as well. Finally, the use of Medicaid waivers adapted for people with dementia will be explored.

Banks and financial institutions can collaborate to address issues related to LTSS financing and prevention of financial abuse or undue influence for those who lack capacity due to cognitive decline.

#### **Strategy 4 - Maintain the dignity, safety and rights of people with ADRD and their caregivers.**

People with dementia are more vulnerable to challenges to their dignity, safety and rights. As cognitive functioning declines, they lack capacity to protect themselves and become dependent upon others for their well-being. To ensure that their physical, psychological, financial and legal protections are in place, partnerships will be encouraged with legal service providers, the Alzheimer's Association Aloha Chapter, Hawaii's ADRCs, Hawaii's first responders, financial institutions, Adult Protective Services, law enforcement, Hawaii's Long-Term Care Ombudsman program, county prosecutors, and the Office of the Public Guardian.

It is again important to involve the person with dementia in earlier stages, when they still have capacity to make important decisions about their wishes for care – another reason why early diagnosis is recommended. It is important that the wishes of the person with ADRD are respected and followed, and the patient kept safe as the disease progresses.

Other legal recommendations include:

- Educate legal professionals about working with people with ADRD, including public and private guardians
- Educate other groups/professionals and the general public having direct contact with persons with dementia on legal issues important to dementia, like advance care planning, Physician Orders for Life-Sustaining Treatment (POLST), Durable Power of Attorney for Healthcare; fiduciaries managing finances for people with dementia
- Expand training in legal, safety and elder abuse issues to address the needs of individuals living in LTSS settings in Hawaii, such as nursing homes, assisted living facilities, care homes and foster homes
- Incorporate elder abuse awareness into Hawaii's aging network activities

- Explore collaborations to provide quick, free or affordable, adequate and accessible legal services to all affected by ADRD, statewide
- Encourage the use of mediation and family counseling services to resolve conflicts that could lead to costly legal fees
- Address barriers to a speedy and cost effective process for guardianship and/or conservatorship proceedings in the Hawaii court system
- Make other statutory changes in Hawaii law that would benefit people with dementia, including the Hawaii Physician Orders for Life Sustaining Treatment (POLST) law

**Strategy 5 - Assess and address the housing needs of people with ADRD.**

Hawaii is now considered the state with the highest cost of living in the nation. This includes the highest prices for gasoline, utilities, insurance, rentals and homes (CNBC, 2013). A Kaiser Foundation study showed that 19% of seniors in Hawaii are living in poverty. Fifty-five percent of Hawaii seniors have incomes below 200% of poverty (Levinson et al, 2013).

Efforts will be made to explore affordable housing models and options in Hawaii that would be accessible for those living with dementia as they age in place.

**Strategy 6 - Improve safety for people with ADRD and their care partners.**

Across the country, an estimated 800,000 people with Alzheimer’s live alone (Alzheimer’s Association, 2013a). They are at greater risk of falling, self-neglect, and wandering without help. Even for those living with their family or care partners, efforts should be made to educate them on falls prevention, as well as offering home safety assessments, and how to monitor those that wander from home. The Alzheimer’s Association Aloha Chapter has a Medic Alert + Safe Return Program (See Hawaii Resources).

When a disaster strikes, there are clear Federal Emergency Management Agency (FEMA) guidelines for sheltering people with dementia and their caregivers, which should be in place in Hawaii.

Also, efforts will be made to develop Hawaii’s crisis capacity for caregivers who are burnt out or ill, or when the person with dementia is having severe behavioral issues. Presently, there is little or no crisis intervention or safe and affordable emergency respite options in the state for these situations.

Based on the island of Hawaii, Project Lifesaver’s mission is to provide timely response to save lives and reduce potential injury for adults and children who may wander due to Alzheimer’s, autism, and other related cognitive conditions. The Hawaii Fire Department implemented this program in 2007 with a Council member’s contingency fund. In 2010, the Hawaii County Office on Aging secured a grant to continue the program. They do public outreach and provide families with pro bono tracking equipment and regular maintenance visits. To date, no one who is on the program was ever lost for any period of time. In 2011, the County of Maui began the program in their community with the assistance of Hawaii Fire Department.



*Hawaii Fire Department staff with a neighborhood friend*

## GOAL 4: Enhance Public Awareness and Engagement

By 2025, the public will be well-educated about brain health and dementia, risk factors, recognition of early signs of dementia, and behavioral issues – and are able to maintain good health practices and appropriately access resources when necessary.

Public awareness of ADRD is one of the most recommended goals of all state, national, and world plans. The fear and stigma associated with dementia are compounded by a lack of knowledge and public education about the disease, its stages, the treatments, how to support caregivers, and where to get services. Consequently, the disease and how to communicate with someone living with dementia are misunderstood by many. Awareness and education should start with young people, in schools and universities.

Hawaii's unique cultural traditions and island environment would benefit from an innovative approach to community involvement called "Dementia Friends" or "dementia friendly communities" that are being piloted and expanded with great success in Minnesota, San Francisco, Japan, Britain, Scotland, and Australia.

### Strategy 1 - Educate and engage the public about ADRD.

Presently in Hawaii, there are no public awareness campaigns being conducted specifically on ADRD. Community resources are not publicized well enough and are hard to navigate. Education is needed on a wide range of topics related to dementia.

In order to reduce stigma, Hawaii partners will conduct an education and public awareness campaign with positive and clear messages, focusing on early and accurate diagnosis, risk factors, the ten warning signs, brain health, difficult behaviors and the importance of advance care planning and caregiver coping strategies.

This will involve branding and developing media relationships for effective communication in all markets. It will also include the creation of an interactive, on-line, one-step repository of Hawaii dementia resources and activities, information links, and news.

There will be an effort to rally community support and participation in a Hawaii "Dementia Friendly Communities" initiative, based on innovative ideas from other states and countries around the world. This movement seeks to give people with dementia a voice on how communities and infrastructure can respect and accommodate their special needs for the best quality of life.



"The best quality of life and care for someone with dementia is a loving environment promoting safety and dignity. Persons with dementia will continue to be a part of the community and engage in activities that they are capable of doing."

- *Ritabelle Fernandes, MD, MPH,*  
*Medical Director, Kokua Kalihi Valley,*  
*Key Informant Survey*

## GOAL 5: Improve Data to Track Progress

---

By 2025, Hawaii will have identified measurable indicators to track progress in reaching its goals and objectives, and have in place a system for collecting the data and monitoring the implementation of its action plan.

There is a general lack of data specific to dementia in Hawaii. Recent sources include the 2011 Behavioral Risk Factor Surveillance Survey (BRFSS) cognitive module (see Appendix H for module and results), the Alzheimer's Association's 2013 Alzheimer's Disease Facts and Figures (2013a), the Hawaii Dementia Caregiver Survey (see Appendix G for survey instruments and results), and the key informant survey conducted by the ADRD Task Force (see Appendix J for survey instrument and results). There may be isolated data collection in Hawaii research studies or in hospitals and health plans, but the data is not unified. Any effort to seek out better data will involve a collaboration of all stakeholders.

### **Strategy 1 - Identify opportunities for improved data collection and analysis on ADRD in Hawaii.**

The state will collaborate with agencies and organizations that have an interest in developing a better surveillance system for dementia. A key component of this surveillance is Hawaii's BRFSS Cognitive Impairment and Caregiver modules.

Funding will be sought to include the Cognitive Impairment and Caregiver modules in the annual BRFSS surveys, possibly bi- or triannually.

### **Strategy 2 - Monitor progress on the Hawaii State Plan on ADRD.**

Hawaii will develop an implementation plan specifying the tasks required for achieving each goal, key milestones, and the timelines for achieving them. The successful implementation of this Plan will be dependent on the participation and contributions of public and private organizations. Hawaii's state plan will be updated annually, and will form an Advisory or Oversight Committee.

As part of implementation, community feedback, including people with early stage dementia, will be sought out via public and private listening sessions, focus groups and stakeholder meetings.



## IV. NEXT STEPS: DISCUSSION

The following activities will take place as next steps in the progress of the Hawaii State Plan for ADRD.

Hawaii will develop an implementation work plan specifying the tasks and timelines required for achieving each goal, identify priorities and key milestones. The priorities and actions will be measurable. The successful implementation of this plan will be dependent on the participation and contributions of public and private organizations. An Advisory Council or Oversight Committee will be formed to review and monitor goals, strategies and implementation of the plan.

Hawaii's ADRD Plan is a living document and will be updated annually. As part of implementation, ongoing community feedback will be sought, including people living with dementia who are able and wish to participate. This will happen via public and private listening sessions, interviews, focus groups and stakeholder meetings. A community survey on dementia may be disseminated.

There are no mandated policy recommendations in this initial plan, but there may be in the future. Eventually, important aspects of the plan may be translated into public policy recommendations through legislation or regulation.

Stakeholders will be reconvened in early 2014 to discuss next steps for the state plan and create a mission statement. Champions of key issues will be identified and workgroups or committees formed to discuss and oversee implementation of the workplan. New committees could include: data stakeholders; geriatric-psychiatric and crisis capacity in Hawaii; quality of care standards and measures; Hawaii memory clinics; early detection and screening tools, accurate diagnosis; legal issues; financial issues; public awareness; dementia caregiver support; safety and disaster preparedness.

Initial work will begin to create an interactive, centralized dementia-specific Hawaii website. Electronic communications will keep the growing Hawaii Dementia Coalition informed about Hawaii and national activities related to ADRD.

The Hawaii Executive Office on Aging will continue to provide staff support to keep implementation moving forward, convene groups, set agendas and identify champions.

Additionally, EOA and strategic partners will collaborate to: celebrate and publicize the state plan; inventory existing statewide services and gaps to being dementia capable; and, seek funding and partners for a public awareness campaign. September will be proclaimed Hawaii Alzheimer's Month and September 21 Hawaii Alzheimer's Day, to align with World Alzheimer's Month and Day.



“To whatever extent possible - and this will change over time - those parts of the person which are the person should be recognized, celebrated, and cherished. The person with dementia is in the process of losing himself or herself. What a terrible and frightening thing this must be! So, the rest of us need to hold on to the patient's personhood when we can, and have as much patience and grace as we can muster when facing the losses caused by the disease.

- Anthony Lenzer, PhD, Family Caregiver, Coordinator, Hawaii Family Caregiver Coalition, Key Informant Survey

## REFERENCES

- AARP. (2012a). *Across the States 2012: Profiles of Long-Term Services and Supports* (9th ed.). Washington, DC: Author.
- AARP. (2012b). 2012 AARP Survey of Hawaii 50+ Residents on Long-Term Care.
- Abbott, R. D., White, L. R., Ross, G. W., Masaki, K. H., Curb, J. D., & Petrovitch, H. (2004). Walking and dementia in physically capable elderly men. *Journal of the American Medical Association*, 292(12), 1447-1453.
- Alzheimer's Association. (2013a). *2013 Alzheimer's Disease Facts and Figures*. Retrieved from [http://www.alz.org/alzheimers\\_disease\\_facts\\_and\\_figures.asp](http://www.alz.org/alzheimers_disease_facts_and_figures.asp).
- Alzheimer's Association. (2013b). Combating Alzheimer's Disease: A Public Health Agenda. Retrieved from [http://www.alz.org/documents\\_custom/public-health/public\\_health\\_agenda\\_brochure-2013.pdf](http://www.alz.org/documents_custom/public-health/public_health_agenda_brochure-2013.pdf).
- Alzheimer's Association. (2013c). Mild Cognitive Impairment. Retrieved from <http://www.alz.org/dementia/mild-cognitive-impairment-mci.asp>. 2013.
- Alzheimer's Association. (2013, March). 2013 Alzheimer's disease facts and figures. Factsheet. Retrieved from [http://www.alz.org/documents\\_custom/2013\\_facts\\_figures\\_fact\\_sheet.pdf](http://www.alz.org/documents_custom/2013_facts_figures_fact_sheet.pdf)
- Alzheimer's Association. (n.d.a). Changing the Trajectory of Alzheimer's Disease: A National Imperative. Retrieved in December 2013 from [http://www.alz.org/alzheimers\\_disease\\_trajectory.asp](http://www.alz.org/alzheimers_disease_trajectory.asp).
- Alzheimer's Association. (n.d.b). *Cognitive Decline in Hawaii*. Retrieved in December 2013 from [http://www.alz.org/documents\\_custom/public-health/hawaii.pdf](http://www.alz.org/documents_custom/public-health/hawaii.pdf).
- Alzheimer's Association. (n.d.c). Down Syndrome. Retrieved December 2013 from [www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp](http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp).
- Alzheimer's Association. (n.d.d). *Health Care Reform and Alzheimer's Disease*. Retrieved in November 2013 from [http://www.alz.org/living\\_with\\_alzheimers\\_healthcare\\_reform.asp#insurance](http://www.alz.org/living_with_alzheimers_healthcare_reform.asp#insurance).
- Alzheimer's Association. (n.d.e). *Treatments for Alzheimer's disease*. Retrieved in November 2013 from [http://www.alz.org/alzheimers\\_disease\\_treatments.asp](http://www.alz.org/alzheimers_disease_treatments.asp).
- Alzheimer's Association. (n.d.f). What You Can Do Now: Factors You May be Able to Influence. Retrieved October 2013 from [http://www.alz.org/alzheimers\\_disease\\_causes\\_risk\\_factors.asp#whatyoucando](http://www.alz.org/alzheimers_disease_causes_risk_factors.asp#whatyoucando).
- Alzheimer's Association and Centers for Disease Control and Prevention. (2013). *Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*. Chicago, IL: Alzheimer's Association. Retrieved from <http://www.cdc.gov/aging/healthybrain/roadmap.htm>.
- Alzheimer's Disease International. (2011). *World Alzheimer's Report 2011: The Benefits of Early Intervention: The benefits of early diagnosis and intervention, Executive Summary*. Retrieved from <http://www.alz.co.uk/research/world-report-2011>.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Retrieved from [www.psych.org/practice/dsm/dsm5](http://www.psych.org/practice/dsm/dsm5).
- Centers for Disease Control and Prevention. (2013). *Cognitive Impairment Module: Behavioral Risk Factor Surveillance System (BRFSS)*. Retrieved from <http://www.cdc.gov/aging/healthybrain/surveillance.htm>.
- Centers for Disease Control and Prevention. (2013, July 19). State-specific healthy life expectancy at age 65 years – United States, 2007–2009. *Morbidity and Mortality Weekly Report*, 6(28), 561-566. Retrieved from [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6228a1.htm?s\\_cid=mm6228a1\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6228a1.htm?s_cid=mm6228a1_w).
- Centers for Medicare and Medicaid Services. (2013, August 27). New data show antipsychotic drug use is down in nursing home national wide. Retrieved from [www.cms.gov/Newsroom/MediaReleaseDatabase/Press-Releases/2013-Press-Releases-Items/2013-08-27.html](http://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-Releases/2013-Press-Releases-Items/2013-08-27.html).
- Douglas, S., James, I., & Ballard, C. (2004) Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment*, 10, 171-177.
- Genworth. (2012). *Genworth 2013 Cost of Care Survey* (10th ed.). Retrieved from [https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/130568\\_032213\\_Cost%20of%20Care\\_Final\\_nonsecure.pdf](https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/130568_032213_Cost%20of%20Care_Final_nonsecure.pdf)
- Hawaii Long-Term Care Commission. (2012, January). *Long-Term Care Reform in Hawaii: Report of the Hawaii Long-Term Care Commission*, Final Report. Honolulu, HI.



- Hawaii State Department of Health. Executive Office on Aging & Kapiolani Community College. Kupuna Educational Center. (2013, November) Hawaii's 2020 Vision: The State of Active Aging.
- Hawaii Workforce Development Council, State of Hawaii. (2011, November). *Hawaii's Healthcare Workforce 20/20 Plan & Report: Addendum to the Comprehensive State Plan for Workforce Development 2009-2014*. Honolulu, HI.
- Home Instead Senior Care. (2012, November 13). Americans rank Alzheimer's as most feared disease, according to new Marist poll for Home Instead Senior Care. Retrieved from <http://www.homeinstead.com/News/Pages/Article.aspx?Filter1Field=ID&Filter1Value=99>.
- Hurd, M., Martorell, P., Delavande, A., Mullen, K., & Langa, K. (2013). Monetary costs of dementia in the United States. *The New England Journal of Medicine*, 368(14), 1325-1334.
- Huybrechts, K. F., Gerhard, T., Crystal, S., Olfson, M., Avorn, J., Levin, R., Lucas, J. A., & Schneeweiss, S. (2012, February). Differential risk of death in older residents in nursing homes prescribed specific antipsychotic drugs: population based cohort study. *BMJ*, 344(e977), 1-12. doi:<http://dx.doi.org/10.1136/bmj.e977>.
- Kakugawa, F. (2012). *Mosaic Moon. Caregiving Through Poetry: Easing the Burden of Alzheimer's Disease* (2nd ed.). Honolulu, HI: Watermark Publishing, 31-32.
- Launer, L. J., Ross, G. W., Petrovitch, H., Masaki, K., Foley, D., White, L. R., & Havlik, R.J. (2000). Mid-life blood pressure and dementia: The Honolulu-Asia Aging Study. *Neurobiology of Aging*, 21(1), 49-55.
- Levinson, Z., Damico, A., Cubanski, J., & Neuman, P. (2013, May 20). *A State-by-State Snapshot of Poverty Among Seniors: Findings from Analysis of the Supplemental Poverty Measure*. The Henry J. Kaiser Family Foundation. Retrieved from <http://kff.org/medicare/issue-brief/a-state-by-state-snapshot-of-poverty-among-seniors/>.
- Lourida, I., Thompson-Coon, J., Purandare, N., Ukoumunne, O. C., & Llewellyn, D. J. (2013). Mediterranean diet, cognitive function, and dementia: a systematic review. *Epidemiology*, 24(4): 479-89.
- Lu, B.Y., Onoye, J.M., Toohey, T.P., Cole, R. (2011, May). *Increased Elderly Utilization of Psychiatric Emergency Services in Honolulu: A Reflection of the Mental Health Crisis Facing Our Nation's Aging Population*. Poster presented at the American Psychiatric Association conference in Honolulu, HI.
- MetLife Mature Market Institute. (2012, November). *Market Survey of Long-Term Care Costs: The 2012 MetLife Market Survey of Nursing Homes, Assisted Living, Adult Day Care, and Home Care Costs*. New York: Author. Retrieved from <https://www.metlife.com/assets/cao/mmi/publications/studies/2012/studies/mmi-2012-market-survey-long-term-care-costs.pdf>.
- Petersen, R.C. (2013, December). *Understanding Alzheimer's Disease and Dementia*. [PowerPoint slides] Presentation at the 2013 Hawaii HCBS Conference: A National Perspective for Local Aging and Disability Professionals, Honolulu, HI.
- Petersen, R. C., Roberts, R. O., Knopman, D. S., Geda, Y.E., Cha, R.H., Pankratz, V. S., Boeve, B. F. Tangalus, E. G., Irnik, R. J. & Rocca, W. A. (2010). Prevalence of mild cognitive impairment is higher in men: The Mayo Clinic Study of Aging. *Neurology*, 75(10), 889-897.
- Tani, C. (2013, September 8). When Alzheimer's strikes. *Honolulu Star-Advertiser*, F1, F4-F5.
- United Kingdom Department of Health. (2013, December 12). *G8 Dementia Summit Concludes with International Agreement to Work Together*. Retrieved from <http://dementiachallenge.dh.gov.uk/2013/12/12/g8-dementia-summit-agreements/>.
- United States Department of Health and Human Services. National Institutes of Health. National Institute of Neurological Disorders and Stroke. (2013, November 29). The Dementias: Hope through Research. Retrieved from [http://www.ninds.nih.gov/disorders/dementias/detail\\_dementia.htm](http://www.ninds.nih.gov/disorders/dementias/detail_dementia.htm).
- United States Department of Health and Human Services. Administration on Aging. (n.d.a). Alzheimer's Disease Supportive Services Program. Retrieved in November 2013 from [www.aoa.gov/AoA\\_Programs/HPW/Alz\\_Grants/](http://www.aoa.gov/AoA_Programs/HPW/Alz_Grants/).
- United States Department of Health and Human Services. Office of the Assistant Secretary for Planning and Evaluation. (n.d.b). National Plan to Address Alzheimer's Disease: 2013 Update. Retrieved November 2013 from <http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.pdf>.
- United States Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Healthy People 2020. (n.d.c). *Dementias, Including Alzheimer's Disease*. Washington, DC. Retrieved December 2013 from <http://healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=7>.
- Weimer, D. L. & Sager, M. A. (2009). Early identification and treatment of Alzheimer's disease: social and fiscal outcomes. *Alzheimer's Dement.*, 5(3), 215- 226. Retrieved from doi:10.1016/j.jalz.2009.01.028.

## V. ACKNOWLEDGEMENTS AND HAWAII RESOURCES

### PRODUCTION TEAM

**Jennifer Chomko**

Practicum Student Intern, Executive Office on Aging  
Hawaii Department of Health

**Heather Chun, MSW**

Lifespan Respite Care Program Coordinator  
Executive Office on Aging  
Hawaii Department of Health

**Jessica Fabrigas**

AmeriCorps VISTA Member, Executive Office on Aging  
Hawaii Department of Health

**David Kanno**

Planner, Executive Office on Aging  
Hawaii Department of Health

**Bum Jung Kim, MSW, PhD**

Assistant Professor  
Myron B. Thompson School of Social Work  
University of Hawaii

**Tania Kuriki, MPH**

Statistician, Executive Office on Aging  
Hawaii Department of Health

**Wesley Lum, PhD, MPH**

Director, Executive Office on Aging  
Hawaii Department of Health

**Jody Mishan**

Coordinator, State Plan on ADRD  
Executive Office on Aging  
Hawaii Department of Health

**Maeona Mendelson, PhD, MSW**

Member, Policy Advisory Board for Elder Affairs  
Director, Intergenerational Center  
Chaminade University of Honolulu

**Charles Nagatoshi, PhD**

Evaluator, Executive Office on Aging  
Hawaii Department of Health

**Florentina Salvail, MSc**

Chief, Health Risks Epidemiology  
and Surveillance Section  
Hawaii Department of Health

**Lorien Yancura, PhD**

Associate Professor  
Department of Family & Consumer Science  
University of Hawaii

### DESIGN

**Allan Kosaka**

Printing Concepts of Hawaii, Inc.

### TASK FORCE AND WORKGROUP MEMBERS

**Iqbal “Ike” Ahmed, MD, FRCPsych**

Faculty Psychiatrist, Tripler Army Medical Center  
Clinical Professor of Psychiatry &  
Geriatric Medicine  
University of Hawaii

**Alexandra Au, MPH**

Program Director  
Leahi Adult Day Health Center

**Linda Axtell-Thompson, DBioethics, MBA**

Assistant Vice President, Strategy Management  
Hawaii Medical Services Association

**Humberto Blanco, MA**

Program Coordinator  
Alzheimer's Association  
Kauai Office

**Waynette Cabral**

Member, Policy Advisory Board for Elder Affairs  
Executive Administrator  
Hawaii State Council on Developmental Disabilities

**Bonnie Castonguay, RN**

Co-Founder and Executive Vice President  
Hookele Health Innovations

**Carene Chrash, MSG**

Manager, Service Coordination  
Ohana Health Plan

**Heather Chun, MSW**

Program Director, Lifespan Respite Program  
Executive Office on Aging

**Norma Circle**

Program Specialist, Maui County Office on Aging

**Sue Cornish, RN, MPH, CMC**

(Certified Care Manager)  
Case Manager, Gerontological Nurse  
Eldercare Resources, Inc.

**Rebecca Drake, MSW**

ADRC Client Service Coordinator  
Elderly Affairs Division, City & County of Honolulu

**Ritabelle Fernandes, MD, MPH**

Internist and Geriatrician  
Kokua Kalihi Valley Comprehensive  
Family Services  
Associate Professor  
Department of Geriatric Medicine  
John A. Burns School of Medicine  
University of Hawaii

**David Fitzgerald**

President, Hale Kuike

**Bret Flynn, MD, MPH**

Geriatric Medicine, Hospice & Palliative Care  
Queen's Health Care Centers

**Thomas Harding, PsyD, MA**

Forensic Neuropsychologist  
Brain Rehabilitation Specialist  
Adult Mental Health Division  
Hawaii Department of Health  
Director of Neuropsychology  
Hawaii Pacific Neuroscience

**Sister Norberta J. Hunnewinkel,****OSF, LCSW**

Franciscan Adult Day Center

**Percy Ihara**

Publisher/Editor, Generations Magazine

**Myra Ikeda**

Project Dana

**Kathy Ishihara, RN**

Member, Policy Advisory Board for Elder Affairs  
Nurse Consultant  
Hawaii Department of Human Services  
Med-QUEST Division, Health Care Services

**Jeannette Koijane, MPH**

Executive Director, Kokua Mau: Hawaii Hospice &  
Palliative Care Organization

**Joy Kurihara, GNP, APRN-RX**

Geriatric Medicine, Straub Clinic & Hospital

**Kore Liow, MD, FACP, FAAN**

Director, Hawaii Pacific Neuroscience  
Clinical Professor of Neurology  
John A. Burns School of Medicine  
University of Hawaii

**Kamal Masaki, MD**

Department Chair, Professor  
John A. Burns School of Medicine  
Department of Geriatric Medicine

**John McDermott, LSW, ACSW, MDiv**

State Long-Term Care Ombudsman  
Hawaii Executive Office on Aging  
Department of Health

**Elizabeth Meahl, MPH**

Elderly Services Department Director  
ALU LIKE, Inc.

**Tricia Medieros**

Regional Director, The Plaza Assisted Living  
Board Chair, Alzheimer's Association Aloha Chapter

**Nancy Moser, APRN**

Program Specialist  
Executive Office on Aging  
Hawaii Department of Health

**David Nakamaejo, MEd**

President, Comforting Hands Senior Care

**Lavonda Mee-Lee Nakamoto, MD**

Medical Director, Home Based Primary Care  
Department of Veterans Affairs  
Pacific Islands Health Care System

**Eryn Nakamura, LCSW**

Director of Social Services,  
Community Case Management Corporation

**Rose Nakamura**

Co-Founder, Administrator, Project Dana

**Bobbie Onzuka-Anderson, MSW**

Non-Institutional Care Program Coordinator &  
Geriatric Outpatient Clinic Social Worker  
Department of Veterans Affairs  
Pacific Islands Health Care System

**Alan Parker**

Member, Policy Advisory Board for Elder Affairs  
Executive on Aging, Hawaii County Office of Aging

**Christine Payne, MBA**

Executive Director and CEO  
Alzheimer's Association, Aloha Chapter

**James H. Pietsch, Esq**

Professor of Law, Director, University of Hawaii  
Elder Law Program  
Adjunct Professor of Geriatric Medicine & Psychiatry  
John A. Burns School of Medicine

**June Renaud**

Aging Program Planner  
County of Kauai Agency on Elderly Affairs

**Chris Ridley, LCSW**

Director of Social Services, Life Care Center of Hilo  
Hawaii County Program Coordinator  
Alzheimer's Association Aloha Chapter

**Stephanie Rizzo-Murray, MSW, LCSW**

Hospice Social Worker  
St. Francis Healthcare System of Hawaii

**George Web Ross, MD**

Veterans Administration Pacific Islands  
Health Care System, Neurology

**Rae Seitz, MD**

Medical Director  
Hawaii Medical Services Association

**Gary Simon**

Member, Policy Advisory Board for Elderly Affairs  
Executive Director, St. Francis Hospice

**Deborah Stone-Walls, MC, LMHC, CSAC**

Member, Policy Advisory Board for Elder Affairs  
Executive on Aging  
Maui County Office on Aging

**Audrey Suga-Nakagawa, MPH**

ASN Consulting Services

**Scott C. Suzuki, JD, MPH**

Scott C. Suzuki, Attorney at Law

**Kathy Suzuki-Kitagawa**

Chief Operating Officer  
Hawaii Primary Care Association

**Kealoha Takahashi**

Executive on Aging  
County of Kauai Agency on Elderly Affairs

**Steven Tam**

Director of Advocacy, AARP Hawaii

**Valorie E. Taylor, LBSW**

Member, Policy Advisory Board for Elder Affairs  
Associate Director, Bayada Home Health Care

**John A. Hau'oli Tomoso, MSW, ACSW, LSW**

Member, Policy Advisory Board for Elder Affairs  
Executive Director, Tri-Isle Resource Conservation  
and Development Council, Inc.

**Sara Tompkison, LCSW**

Caregiver Support Coordinator  
Department of Veterans Affairs  
Pacific Islands Health Care System

**Cristina Valenzuela, MPA**

Project Developer  
Catholic Charities Hawaii

**Aida Wen, MD, CMD**

Associate Professor  
Department of Geriatric Medicine  
University of Hawaii  
John A. Burns School of Medicine  
Medical Director  
St. Francis Hospice Palliative Care Program

**Deborah Wills, MBA**

Aging Program Planner  
Hawaii County Office of Aging

**Tracey S. Wiltgen, Esq**

Executive Director  
The Mediation Center of the Pacific, Inc.

**Rachael Wong, DrPH**

Vice President & COO  
Healthcare Association of Hawaii

**Loriena Yancura, PhD**

Associate Professor  
Department of Family & Consumer Science  
University of Hawaii

**Michael W.K. Yee, CFP, CFS, CRPC**

Financial Advisor, Ameriprise Financial Services, Inc.

**Valerie Yontz, RN, MSN, MPH, PhD**

Associate Specialist & Practice Coordinator  
Department of Public Health  
University of Hawaii

**Pamela Yuen,****MA Counseling, MA Ed/Admin**

Director of Programs  
Alzheimer's Association, Aloha Chapter

**CONTENT ADVISORS  
AND CONTRIBUTORS****Della Au Belatti, JD**

Hawaii State Representative  
Chair, House Health Committee

**Patricia Lanoie Blanchette, MD, MPH**

CEO, UCERA: University Clinical  
Education and Research Associates

**Bradley Chun, MD**

Assistant Clinical Director, Kokua Kalihi Valley

**Suzanne Chun Oakland,**

State Senator, Chair Human Service Committee

**David Derauf, MD, MPH**

Executive Director  
Kokua Kalihi Valley Comprehensive Family Services

**Jesse Ebersole**

Fire Medical Specialist  
Hawaii County Fire Department

**David Fray, DDS, MBA**

Chief, Developmental Disabilities Division  
Hawaii Department of Health

**Lynn Fallin**

Deputy Director, Behavioral Health Administration  
Hawaii Department of Health

**Mark A. Fridovich, PhD, MPA**

Administrator, Adult Mental Health Division  
Hawaii Department of Health

**Debra Fuller**

Care Coordination Director, AlohaCare

**Mary Gadam, BSN, RN**

Public Health Nurse, Hawaii Department of Health

**Josh Greene, MD**

State Senator, Chair Senate Health Committee

**Steve Hansen**

Administrator, Alii Community Care  
dba: Roselani Place, Maui

**Toni Hathaway, LSW**

Education Coordinator, Kupuna Education Center  
Kapiolani Community College

**Jerris Hedges, MD, MS, MMM**

Dean, University of Hawaii  
John A. Burns School of Medicine

**Peter Hirai, CEM**

Deputy Director  
Department of Emergency Management  
City & County of Honolulu

**Earl S. Hishinuma, PhD**

Professor & Associate Chair of Research  
Department of Psychiatry, University of Hawaii

**Karen Ho, MBA**

Comprehensive Health Planning Coordinator  
Hawaii State Health Planning and  
Development Agency  
Hawaii Department of Health

**Susan B. Hunt, MHA**

Beacon Grant Project Director  
CEO Hawaii Island Beacon Community

**Brian S. Ishikawa, CPP, CFSSP**

Senior Vice President  
Director of Corporate Security  
Bank of Hawaii

**Michael J. Keaney and Staff**

Administrator  
Oahu Adult Protective and  
Community Services Section  
Hawaii Department of Human Services

**Michael Komeya, MD**

Medical Director, Senior Behavioral Health  
Adult and Geriatric Psychiatry  
Wahiawa General Hospital

**Bernadette Ledesma, MPH, NHA**

Administrator, Pearl City Nursing Home

**Jeanne Lee**

Consumer

**Clarence Liu**

Chaplain (ret. Hospice Hawaii)

**Anthony Lenzer, PhD**

Member, Policy Advisory Board on Elder Affairs  
President, Hawaii Family Caregiver Coalition

**Anna Loengard, MD**

Chief Medical Officer  
St. Francis Community Health Services  
St. Francis Healthcare System of Hawaii

**Brett Lu, MD, PhD**

Director of Community Geriatric Medicine  
Queen's Hospital  
Assistant Professor  
John A. Burns School of Medicine  
University of Hawaii

**Lexi N. McKay**

Legal Assistant  
Hawaii County Office of the Prosecuting Attorney  
Elder Abuse Prosecution & Prevention Unit

**Lynn Meguro-Reich, MEd**

Educational Specialist  
Office of Curriculum, Instruction & Student Support  
Hawaii Department of Education

**Cindy Lee Meiers, MPH, NHA****Nolan Namba**

Chief Marketing Officer, AlohaCare

**Jane Onoye, PhD**

Assistant Professor, Psychiatry  
John A. Burns School of Medicine  
University of Hawaii

**Laura Paresa, RN**

Registered Nurse, Adult Protective Services  
Maui Unit  
Hawaii Department of Human Services

**Russell Ruderman**

Hawaii State Senator

**Adele Rugg**

Member, Policy Advisory Board for Elder Affairs  
Board Member, Alzheimer's Association  
– Aloha Chapter

**David Sakamoto, MD, MBA**

Deputy Director, Health Resources Administration  
Hawaii Department of Health

**Daniel Saltman, MD**

Internist, Waikiki Health Center

**Marilyn Seely, MPH**

Policy Advisory Board for Elder Affairs

**Susan Narwicz Sherwood, PhD, FAAIDD**

Psychologist, Clinical Interdisciplinary Team  
Developmental Disabilities Division  
Hawaii Department of Health

**Joy Soares, MPA**

Healthcare Transformation Policy Analyst  
Office of the Governor

**Deidre Sumic, RN**

Registered Nurse, Adult Protective and  
Community Services, Hawaii County Division  
Hawaii Department of Human Services

**Peter Sybinksy, PhD**

President and CEO, Hawaii Health  
Information Corporation

**Sharon Taba, MEd**

Senior Producer, Same Small Boat Productions, LLC

**Ken Takeya**

Caregiver

**Diane Terada, MSW, LSW**

Division Administrator  
Catholic Charities Hawaii

**Rowena L. Tiqui**

Executive Director, Kona Adult Day Center, Inc.

**Lori Tsuruda, RN**

Program Specialist  
Program Development Department  
Hawaii Department of Human Services

**Paula Uusitalo**

Executive Director, Hawaii Island Adult Care, Inc.

**Lon White, MD, MPH**

Principal Investigator  
Pacific Health Research & Education Institute

**Steven H. Yoshimura**  
Population Protection Planner  
Hawaii State Civil Defense

**Sara Yuan, PhD**  
Associate Specialist, University of Hawaii  
Center on the Family  
Member, Policy Advisory Board for Elder Affairs

**Suzanne Zaw, RN, MSN, MPH**  
Public Health Nurse, Public Health Nursing Branch  
Hawaii Department of Health

## PHOTO CREDITS

**Cindy Goya**  
**Hale Kuike, LLC**  
**Hawaii County Fire Department**  
**Hawaii Pacific Neuroscience**  
**John A. Burns School of Medicine**  
**Frances Kakugawa**  
**Kokua Kalihi Valley Memory Clinic**  
**Kokua Mau**  
**Kupuna Education Center**  
**The Honolulu Star Advertiser**  
**Ken Takeya**  
**Anita Trubitt**

## SPECIAL THANKS

**Hawaii Medical Service Association (HMSA)**

**Randi Chapman**  
Director, State Affairs, Alzheimer's Association

**Lily Bloom Domingo**  
CommUnity Works, LLC

**Cindy and Mike Goya**

**Cullen T. Hayashida, PhD**  
Kapiolani Community College  
Kupuna Education Center

**Frances Kakugawa**  
Poet, Caregiver

**Gerald T. Kosaki, MICT**  
Battalion Chief, Special Operations  
Hawaii Fire Department

**Catherine Morrison, MPH**  
Senior Associate Director, Public Health  
Alzheimer's Association

**Mark Olds**  
Caregiver

**Ronald C. Petersen, MD, PhD**  
Director  
Mayo Alzheimer's Disease Research Center  
Chair, National Alzheimer's Project Act  
Advisory Council

**Suzie Schulberg and staff**  
Chief Operating Officer, 15 Craigsid

**Michael Splaine**  
Splaine Consulting and Cognitive Solutions LLC

**Ken and Charlotte Takeya**

**Jane Tilly, DrPH**  
Office of Supportive & Caregiver Services  
Administration for Community Living  
Administration on Aging

**Anita Trubitt, LCSW, MSW, MEd**  
Caregiver

## HAWAII RESOURCES

### ALZHEIMER'S ASSOCIATION – ALOHA CHAPTER

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. They are the largest non-profit funder of Alzheimer's research. Their mission: 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.

Services include: information and referral, family care consultations, Medic Alert + Safe Return wanderer's registry and I.D, caregiver training and education, support groups, and professional training. For the Alzheimer's Association - Aloha Chapter, you can call the toll-free number 800-272-3900 during business hours, or for general information, email [alohainfo@alz.org](mailto:alohainfo@alz.org).

#### ALZHEIMER'S ASSOCIATION 24-7 HELPLINE

[http://www.alz.org/we\\_can\\_help\\_24\\_7\\_helpline.asp](http://www.alz.org/we_can_help_24_7_helpline.asp)  
Phone: (800) 272-3900

Serves people with memory loss, caregivers, health care professionals and the public, featuring confidential care consultation and translation for over 170 languages and dialects, and referrals to local community programs

#### ALOHA CHAPTER HEADQUARTERS, OAHU OFFICE

1050 Ala Moana Boulevard, Suite 2610  
Honolulu, Hawaii 96814  
Phone: (808) 591-2771  
FAX: (808) 591-9071  
Website: [www.alz.org/hawaii/](http://www.alz.org/hawaii/)

#### Hawaii

1055 Kinoole Street, Suite 103  
Hilo, Hawaii 96720  
Phone: (808) 981-2111

#### Kauai Office

4303 Rice Street, Suite C2  
Lihue, Hawaii 96766  
Phone: (808) 245-3200  
FAX: (808) 245-9900

#### Maui Office

(serving Maui, Molokai and Lanai)  
270 Hookahi Street, Suite 311  
Wailuku, Hawaii 96793  
Phone: (808) 242-8636  
FAX: (808) 242-8639

## STATE AGENCIES

The Executive Office on Aging (EOA) leads the Hawaii aging network of county area agencies on aging (AAAs), and partners with diverse community resources in preparing for a rapidly growing aging society.

EOA is the only state agency dedicated to older adults, their families and caregivers. EOA provides advocacy for older adults, policy development, program development, planning and funding of support services to older persons, their families and caregivers, and information and education. EOA is advised by the Policy Advisory Board for Elder Affairs to identify issues and solutions, develop position statements, and advocate, among other things.

The Aging & Disability Resource Centers (ADRC) help older adults, individuals with disabilities, and family caregivers find ways to meet long-term support needs to remain living at home as long as possible or in another setting of choice. ADRC options counselors will help to determine eligibility for government paid programs such as Kupuna Care, find private providers, and develop care plans.

### **HAWAII AGING & DISABILITY RESOURCE CENTER (ADRC)**

ADRC Statewide phone: (808) 643-2372

ADRC TTY Line: (808) 643-0899

[www.hawaiiadrc.org](http://www.hawaiiadrc.org)

### **EXECUTIVE OFFICE ON AGING**

No.1 Capitol District

250 South Hotel Street, Suite 406

Honolulu, Hawaii 96813-2831

Phone: (808) 586-0100

FAX: (808) 586-0185

Email: [eo@doh.hawaii.gov](mailto:eo@doh.hawaii.gov)

Website: [www.hawaiiadrc.org](http://www.hawaiiadrc.org)

## HAWAII AREA OFFICES ON AGING (AAAs)

### **Hawaii County**

Kahi Malama - A Place of Caring

Aging & Disability Resource Center

1055 Kinoole Street

Hilo, Hawaii 96720

Phone: Hilo - (808) 961-8626 Kona - (808) 323-4390

FAX: (808) 961-8603

Email: [hcoa@hawaiiantel.net](mailto:hcoa@hawaiiantel.net)

Website: [www.hcoahawaii.org](http://www.hcoahawaii.org)

### **Kauai County**

Kauai Agency on Elderly Affairs

Piikoi Building

4444 Rice Street, Suite 330

Lihue, Hawaii 96766

Phone: (808) 241-4470

FAX: (808) 241-5113

Email: [elderlyaffairs@kauai.gov](mailto:elderlyaffairs@kauai.gov)

Website: [www.kauaiadrc.org](http://www.kauaiadrc.org)

### **Honolulu County**

Elderly Affairs Division

Standard Finance Building

715 South King Street, Suite 200

Honolulu, Hawaii 96813

Phone: (808) 768-7700

FAX: (808) 527-6895

Email online via Website: [www.elderlyaffairs.com](http://www.elderlyaffairs.com)

### **Maui County**

Maui County Office on Aging

2200 Main Street, Suite 547

Wailuku, Hawaii 96793

Phone: Maui - (808) 270-7774 Molokai - (808) 553-5241

Lanai - (808) 565-7114

FAX: (808) 270-7935

Email: [aging@mauicounty.gov](mailto:aging@mauicounty.gov)

## OTHER HAWAII RESOURCES

### **KUPUNA EDUCATION CENTER**

Kapiolani Community College

4303 Diamond Head Road, Kopiko 123

Honolulu, Hawaii 96816

Phone: (808) 734-9108

FAX: (808) 734-9128

Website: [www.kupunaeducation.com](http://www.kupunaeducation.com)

### **UNIVERSITY OF HAWAII ELDER LAW PROGRAM (UHELP)**

2515 Dole Street, Room 201

Honolulu, Hawaii 96822

Phone: (808) 956-6544

FAX: (808) 956-9439

Website: <http://www.hawaii.edu/uhelp/>

## USEFUL LINKS AND RESOURCES

### **The Alzheimer's Association**

[www.alz.org](http://www.alz.org)

### **Alzheimer's Association 24-7 Helpline**

[http://www.alz.org/we\\_can\\_help\\_24\\_7\\_helpline.asp](http://www.alz.org/we_can_help_24_7_helpline.asp)

Phone: 1-800-272-3900

### **Alzheimer's Association Aloha Chapter**

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

### **Alzheimer's Association Research Center Trial Match**

[http://www.alz.org/research/clinical\\_trials/find\\_clinical\\_trials\\_trialmatch.asp](http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp)

### **Alzheimer's Association State Plans**

[http://act.alz.org/site/PageNavigator/state\\_plans.html](http://act.alz.org/site/PageNavigator/state_plans.html)

### **Alzheimer's Association 2013 Facts & Figures**

[www.alz.org/alzheimers\\_disease\\_facts\\_and\\_figures.asp](http://www.alz.org/alzheimers_disease_facts_and_figures.asp)

### **Alzheimer's Disease Education and Referral Center, National Institute on Aging,**

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

### **Alzheimer's Disease International (World Reports)**

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

### **Alzheimer's Disease Supportive Services Program (ADSSP)**

[http://www.aoa.gov/AoARoot/AoA\\_Programs/HPW/Alz\\_Grants/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx)

### **Alzheimer's Foundation of America**

<http://www.alzfdn.org>

### **Alzheimers.gov**

[www.alzheimers.gov](http://www.alzheimers.gov)

### **Alzheimer's Prevention Initiative**

<http://www.endalznw.org>

### **AHRQ, Agency for Healthcare Research and Quality Improvement (dementia links)**

[http://www.innovations.ahrq.gov/innovations\\_qualitytools.aspx?search=dementia](http://www.innovations.ahrq.gov/innovations_qualitytools.aspx?search=dementia)

### **Caregiver Action Network**

<http://caregiveraction.org>

### **Centers for Disease Control: The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health**

<http://www.cdc.gov/aging/healthybrain/roadmap.htm>

### **DASNI International, Dementia Advocacy and Support Network**

<http://www.dasninternational.org>

### **The Dementia Challenge (Britain)**

<http://dementiachallenge.dh.gov.uk>

**Dementia Friendly Communities, Scotland**  
<http://www.adementiafriendlycommunity.com>

**Dementia Friends, Britain**  
<http://www.dementiafriends.org.uk/session#.Uq9qG6lbuKU>

**Hand in Hand, A Training Series for Nursing Homes**  
[www.cms-handinhandtoolkit.info](http://www.cms-handinhandtoolkit.info)

**Hawaii Healthcare Project**  
<http://www.hawaiihealthcareproject.org/index.php/transforming-healthcare/phase-2.html>

**Healthy People 2020: Dementias**  
<http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=7>

**International Alzheimer's Disease Research Portfolio (IADRP)**  
<http://iadrp.nia.nih.gov/cadro-web/>

**LEAD: Leaders Engaged on Alzheimer's Disease**  
<http://www.leadcoalition.org>

**Mayo Clinic Alzheimer's Disease Center**  
<http://www.mayoclinic.com/health/alzheimers-disease/DS00161>

**Meeting of the Minds: Meaningful engagement, support and resources using real time communications for people facing the challenge of dementia**  
<http://minds-meeting.com>

**Minnesota ACT on Alzheimer's website**  
[www.actonalz.org](http://www.actonalz.org)

**Namaste Care for People with Dementia**  
<http://www.namastecare.com>

**National Alliance for Caregiving**  
<http://www.caregiving.org>

**National Alzheimer's Project Act (NAPA) home page, and link to the National Plan to Address Alzheimer's Disease**  
<http://aspe.hhs.gov/daltcp/napa/>

**National Institute on Aging: Caring for a Person with Alzheimer's Disease**  
<http://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease>

**National Task Group on Intellectual Disabilities and Dementia Practices**  
<http://aadmd.org/ntg>

**Partnership for Patients**  
<http://partnershipforpatients.cms.gov>

**Research Match**  
<https://www.researchmatch.org>



# APPENDICES

<b>Appendix A: Types of Dementia</b>	<b>41</b>
<b>Appendix B: Selected Causes of Death</b>	<b>42</b>
<b>Appendix C: Hawaii Demographic Data</b>	<b>43</b>
<b>Appendix D: Ten Warning Signs of Alzheimer’s Disease</b>	<b>45</b>
<b>Appendix E: Importance of Early Diagnosis</b>	<b>45</b>
<b>Appendix F: Cost Estimates for Dementia Care</b>	<b>46</b>
<b>Appendix G: Hawaii Dementia Caregiver Survey</b>	<b>48</b>
Dementia Caregiver Survey Results	48
Dementia Caregiver Survey Instrument	54
<b>Appendix H: 2011 Behavioral Risk Factor Surveillance System (BRFSS) Cognitive Impairment Module</b>	<b>56</b>
Hawaii Cognitive Impairment Module Results	57
Cognitive Impairment Module Survey Instrument	60
<b>Appendix I: American Community Survey, Special Tabulation on Aging</b>	<b>62</b>
<b>Appendix J: Key Informant Survey</b>	<b>63</b>
Key Informant Survey Results	63
Key Informant Survey Instrument	70
<b>References</b>	<b>82</b>



## APPENDIX A - Types of Dementia and their Characteristics

### Alzheimer's disease

*Symptoms:* Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.

### Vascular dementia

*Symptoms:* Impaired judgment or ability to plan steps needed to complete a task is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's.

### Dementia with Lewy bodies (DLB)

*Symptoms:* People with dementia with Lewy bodies often have memory loss and thinking problems common in Alzheimer's, but are more likely than people with Alzheimer's to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features.

### Mixed dementia

In mixed dementia abnormalities linked to more than one type of dementia occur simultaneously in the brain.

### Parkinson's disease

*Symptoms:* Problems with movement are a common symptom early in the disease. If dementia develops, symptoms are often similar to dementia with Lewy bodies.

### Frontotemporal dementia

*Symptoms:* Typical symptoms include changes in personality and behavior and difficulty with language. Nerve cells in the front and side regions of the brain are especially affected.

### Creutzfeldt-Jakob disease

*Symptoms:* Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.

### Normal pressure hydrocephalus

*Symptoms:* Symptoms include difficulty walking, memory loss and inability to control urination.

### Huntington's Disease

*Symptoms:* Include abnormal involuntary movements, a severe decline in thinking and reasoning skills, and irritability, depression and other mood changes.

### Wernicke-Korsakoff SyndromeKorsakoff syndrome

*Symptoms:* Memory problems may be strikingly severe while other thinking and social skills seem relatively unaffected

## APPENDIX B - Selected Causes of Death in Hawaii

Between 2000 and 2010, the percentage change in the number of deaths due to Alzheimer's disease in Hawaii increased by 60.2 percent while the percentage change decreased for heart disease (-6.3%) and stroke (-19.0%). In 2010, the age-adjusted death rate for Alzheimer's in Hawaii was less than half that of the United States as a whole.

**Table B.1. Number and Age-Adjusted Rates for Selected Causes of Death Hawaii, 2000 and 2010**

PRIMARY CAUSE OF DEATH	2000 <sup>1</sup>		2010 <sup>2</sup>		Percent Change from 2000 to 2010
	Number	Age-Adjusted Rate (per 100,000)	Number	Age-Adjusted Rate (per 100,000)	
Total Deaths (All Causes)	8,290	666.7	9,617	589.6	16.0%
Alzheimer's Disease	118	9.8	189	10.5	60.2%
Heart Disease	2,390	191.9	2,239	134.7	-6.3%
Cancer	1,943	154.0	2,266	140.9	16.6%
Stroke	747	60.3	605	35.8	-19.0%

<sup>1</sup> Note. From Deaths: final data for 2000, by Minino, Arias, Kochanek, Murphy, & Smith, 2002, *National Vital Statistics Reports*, 50(15), pp. 96-97.

<sup>2</sup> Note. From Deaths: final data for 2010, by Murphy, Xu, & Kochanek, 2013, *National Vital Statistics Reports*, 61(4), pp. 85-87

**Table B.2. Number and Age-Adjusted Rates for Selected Causes of Death United States, 2000 and 2010**

PRIMARY CAUSE OF DEATH	2000 <sup>1</sup>		2010 <sup>2</sup>		Percent Change from 2000 to 2010
	Number	Age-Adjusted Rate (per 100,000)	Number	Age-Adjusted Rate (per 100,000)	
Total Deaths (All Causes)	2,403,35	872.0	2,468,435	747.0	2.7%
Alzheimer's Disease	49,558	18.0	83,494	25.1	68.5%
Heart Disease	710,760	257.9	597,689	179.1	-15.9%
Cancer	553,091	201.0	574,743	172.8	3.9%
Stroke	167,661	60.8	129,476	39.1	-22.8%

<sup>1</sup> Note. From Deaths: final data for 2000, by Minino, Arias, Kochanek, Murphy, & Smith, 2002, *National Vital Statistics Reports*, 50(15), pp. 96-97.

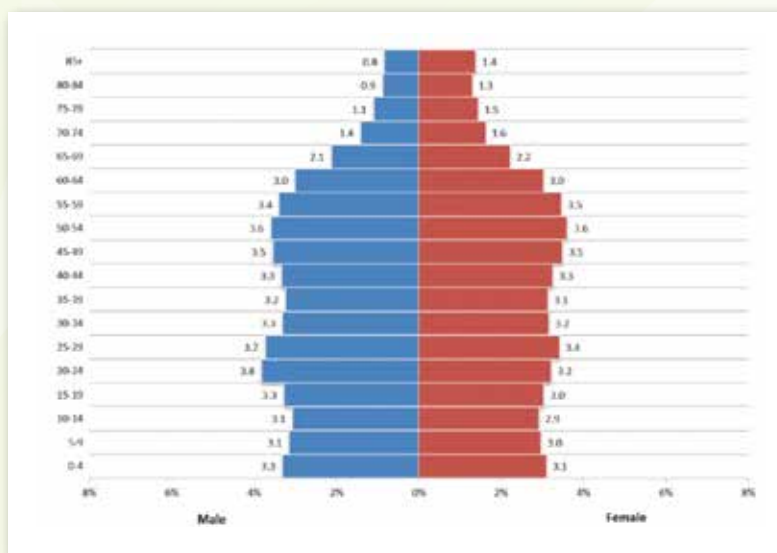
<sup>2</sup> Note. From Deaths: final data for 2010, by Murphy, Xu, & Kochanek, 2013, *National Vital Statistics Reports*, 61(4), pp. 85-87

## APPENDIX C - Hawaii Demographic Data

Hawaii residents have a longer life expectancy than the U.S. In 2030, the over age 65 population in Hawaii is projected to be 88.8 percent higher than the 2010 population. The 2012 American Community population survey showed, relative to the nation, older adults in Hawaii have a number of factors that lowered their risk for Alzheimer’s and dementia. Hawaii’s older adults were less likely to live alone and slightly more likely to have had post-secondary education—both are protective factors against dementia. In addition, Hawaii had proportionately fewer Hispanics and African-Americans, two ethnic groups at greater risk for having Alzheimer’s and dementia.

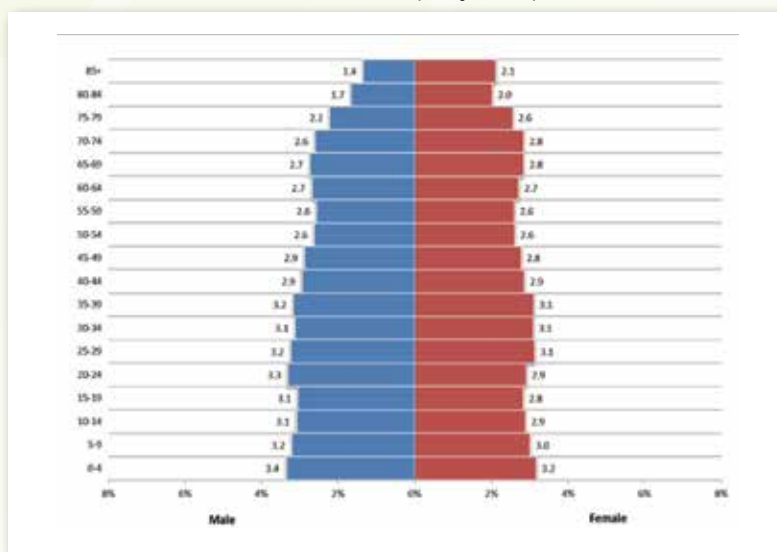
**Table C.1. Population Pyramids: 2010 and 2030**

2010 Hawaii Population by Gender and Age Group  
N=1,360,301



Note. From 2010 Demographic Profile Data by the U.S. Census Bureau (n.d.a).

2030 Hawaii Population by Gender and Age Group  
N=1,602,338 (Projected)



Note. From Population and Economic Projections for the State of Hawaii to 2040 by the Hawaii State Department of Business, Economic Development & Tourism, 2012.

## APPENDIX C - Hawaii Demographic Data

**Table C.2. Demographic Characteristics of Hawaii's Older Adults (Age 65 and Older), 2012**

Characteristic	Hawaii	U.S.
<b>Gender</b>		
Male	44.4%	43.6%
Female	55.6%	56.4%
<b>Race</b>		
One Race		
White	25.9%	84.6%
Black or African American	0.6%	8.6%
American Indian/Alaskan Native	0.1%	0.5%
Asian	58.4%	3.7%
Native Hawaiian/Other Pacific Islander	5.8%	0.1%
Other Race	0.3%	1.5%
Two or More Races	9.0%	1.0%
<b>Hispanic or Latino Origin</b>	2.9%	7.3%
<b>Education Level</b>		
Less than High School Degree	18.8%	20.0%
High School Degree or GED	31.4%	33.5%
Some College or Associate's Degree	24.1%	23.3%
Bachelor's Degree or Higher	25.8%	23.2%
<b>Living Alone</b>	32.4%	43.4%

Note. From 2012 American Community Survey 1-Year Estimates by the U.S. Census Bureau (n.d.b).

**Table C.4. Life Expectancy at Birth (in Years)**

	1930	1940	1950	1960	1970	1980	1990	2000
Hawaii	54	62	70	72	74	78	79	80
United States	60	63	68	70	71	74	75	77

Note. From Life expectancy at birth, Hawai'i vs. U.S by Hawaii Health Information Corporation, (n.d.), *Health Trends in Hawaii*.

## APPENDIX D - Ten Warning Signs of Alzheimer's Disease

Memory loss that disrupts daily life may be a symptom of Alzheimer's or another dementia. The Alzheimer's Association has developed the following 10 warning signs. Individuals who exhibit several of these symptoms should see a physician for a complete clinical evaluation.

1. **Memory loss that disrupts daily life**
2. **Challenges in planning or solving problems**
3. **Difficulty completing familiar tasks at home, at work or at leisure**
4. **Confusion with time or place**
5. **Trouble understanding visual images and spatial relationships**
6. **New problems with words in speaking or writing**
7. **Misplacing things and losing the ability to retrace steps**
8. **Decreased or poor judgment**
9. **Withdrawal from work or social activities**
10. **Changes in mood and personality**

Note. From *2013 Alzheimer's Disease Facts and Figures* by the Alzheimer's Association, (2013).

## APPENDIX E - Importance of Early Diagnosis

Early detection and diagnosis of Alzheimer's is critical for improving the physical, emotional, and financial impacts of disease. Unfortunately, medical providers do not routinely assess the cognitive health of their patients, leading to delayed Alzheimer's diagnosis and post diagnostic care.

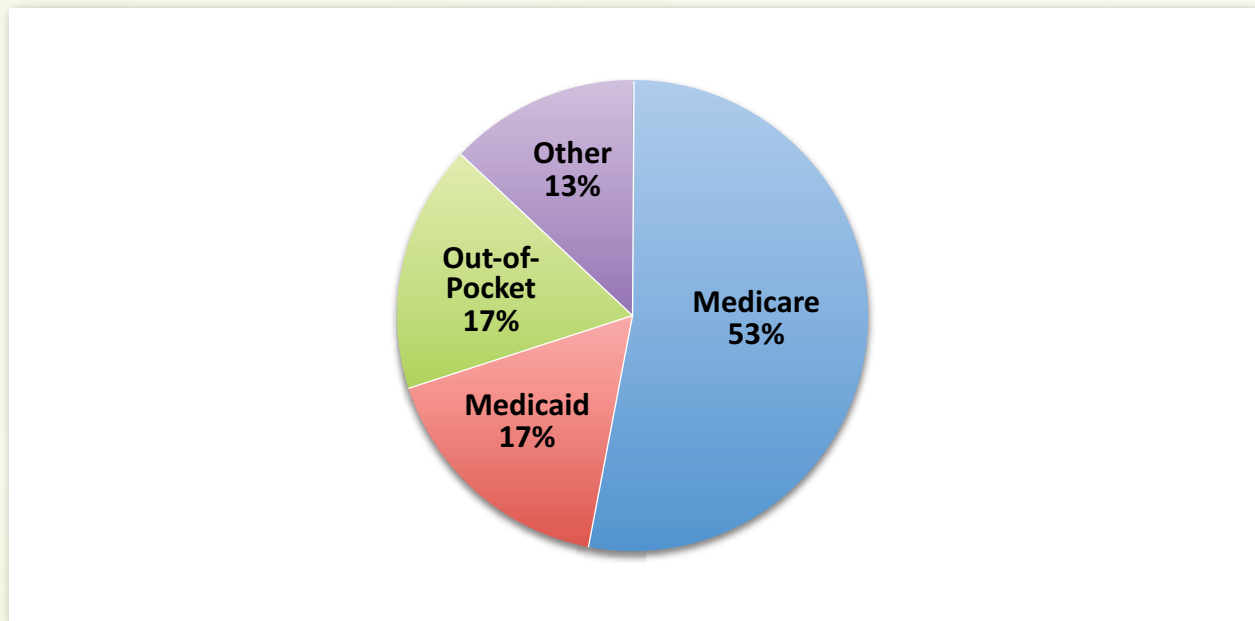
The Alzheimer's Disease International's *World Alzheimer's Report 2011* describes nine benefits of early diagnosis:

1. **Optimize current medical management** – attention to treatable causes, exacerbating factors, and medication review.
2. **Relief gained from better understanding** – validation of concerns, and a framework for understanding the origin and nature of symptoms.
3. **Maximize decision-making autonomy** – the chance to make important decisions about the future while still retaining mental capacity.
4. **Access to services** – timely access to medical care, advice, and support, all of which require a diagnosis.
5. **Risk Reduction** – safety at home, driving assessments, anticipating and avoiding adverse effects of medications.
6. **Plan for the future** – early retirement, financial planning, safety and security issues.
7. **Improve clinical outcomes** – slowing or stabilizing cognitive and functional decline (slow progression of cognitive and functional impairment).
8. **Avoid or reduce future costs** – chiefly through delaying or avoiding transition into a care home.
9. **Diagnosis as a human right** – both to have access to an accurate diagnosis, and to be informed of it or not, according to one's preference.

Note. From *Importance of Early Detection*, Act on Alzheimer's website, (n.d.).

## APPENDIX F - Cost Estimates for Dementia Care

**Figure F.1.** Cost Estimates for Dementia Care for Americans age 65 and Older by Payer, 2013



Note. From 2013 *Alzheimer's Disease Facts and Figures* by the Alzheimer's Association.

**Table F.1.** Cost Estimates for Dementia Care in the U.S., 2010

Type of Care	Average Annual Cost per Person
Nursing Home care	\$13,876
Formal Home Care	\$5,678
Informal Caregiving - Lost Wages	\$13,188
Informal Caregiving - Replacement Costs	\$27,789
Medicare spending	\$2,752
Out-of-Pocket spending	\$6,194

Note. From Monetary costs of dementia in the United States by Hurd et al., 2013, *NEJM*, Table 2, p. 1332.

## APPENDIX F - Cost Estimates for Dementia Care

**Table F.2. Cost Estimates for Facility-based Care, 2012**

Facility Type	Hawaii	United States
Nursing Home care		
Semi-Private Room, Average Daily Rate	\$344	\$222
Private Room, Average Daily Rate	\$384	\$248
Assisted Living Communities, Average Monthly Base Rate	\$4,659	\$3,550

Note.: From the 2012 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs by MetLife, 2012.

**Table F.3. Annual per Person Medicare Payment for Beneficiaries Age 65 and Older for Selected Medical Conditions by Alzheimer's Disease and Related Dementia (ADRD) Status and Type of Service (in 2012 Dollars)**

Type of Service	Medical Condition and Alzheimer's Disease and Dementia Status (ADRD)					
	Coronary Heart Disease		Stroke		Cancer	
	With ADRD	Without ADRD	With ADRD	Without ADRD	With ADRD	Without ADRD
Hospital Care	\$10,312	\$7,410	\$10,160	\$7,875	\$9,135	\$6,198
Physician Care	\$1,718	\$1,314	\$1,669	\$1,419	\$1,567	\$1,202
Skilled Nursing Facility Care	\$4,344	\$1,324	\$4,557	\$2,336	\$3,653	\$989
Home Health Care	\$2,721	\$1,171	\$2,578	\$1,891	\$2,221	\$788
Hospice Care	\$2,347	\$342	\$2,758	\$652	\$2,890	\$592

Note. From 2013 Alzheimer's Disease Facts and Figures by the Alzheimer's Association, 2013.



## APPENDIX G - *Hawaii Dementia Caregiver Survey*

The Hawaii Dementia Caregiver Survey was developed by the ADRD Supports for Family Caregivers Task Force workgroup. The survey was piloted in Honolulu with 35 dementia caregivers in May 2012 and revised. Between August 2012 and June 2013, the revised version of the survey was made available to caregivers through the Web and at caregiver fairs, senior health fairs, senior centers, and other places frequented by older adults. A total of 155 caregivers completed the survey.

**Table G.1. Caregiver Age**

Caregiver Age	Percent of Caregivers (Number)
18 – 44	9.7% (15)
45 – 54	21.9% (34)
55 – 64	25.8% (40)
65 – 74	25.8% (40)
75+	14.2% (22)
Missing	3.2% (5)
Total	100.0% (155)

**Table G.2. Caregiver Gender**

Caregiver Gender	Percent of Caregivers (Number)
Male	19.4% (30)
Female	80.6% (125)
Total	100.0% (155)

**Table G.3. Caregiver Ethnicity**

Caregiver Ethnicity	Percent of Caregivers (Number)
Japanese	36.8% (57)
Caucasian	22.6% (35)
Hawaiian/Part-Hawaiian	1.3% (2)
Filipino	1.3% (2)
Korean	0.6% (1)
Chinese	10.3% (16)
African-American	7.7% (12)
Non-Hawaiian Mix	17.4% (27)
Other	1.9% (3)
Total	100.0% (155)

APPENDIX G - *Hawaii Dementia Caregiver Survey*

**Table G.4. Caregiver Health Status**

Caregiver Health Status	Percent of Caregivers (Number)
Poor	2.6% (4)
Fair	19.4% (30)
Good	60.6% (94)
Excellent	17.4% (27)
Total	100.0% (155)

**Table G.5. Caregiver Health Conditions**

Caregiver Health Condition	Percent of Caregivers <sup>1</sup> (Number)
High blood pressure	36.8% (57)
Heart disease	6.5% (10)
Diabetes	14.8% (23)
Other	38.1% (59)
None	30.3% (47)
Total	126.4% (155)

**Table G.6. Doctor's Diagnosis of Care Recipient**

Doctor's Diagnosis of Care Recipient	Percent of Care Recipients <sup>2</sup> (Number)
Alzheimer's Disease	32.9% (51)
Other Dementia	47.7% (74)
Mild Cognitive Impairment (MCI)	15.5% (24)
Other	29.0% (45)
Missing	12.3% (19)

**Table G.7. Doctor's Diagnosis of Care Recipient**

Caregiver Relationship to Care Recipient	Percent of Caregivers (Number)
Spouse/Partner	16.8% (26)
Parent	55.5% (86)
Grandparent	1.3% (2)
Aunt/Uncle	2.6% (4)
Neighbor	1.3% (2)
Hanai Family	1.3% (2)
Missing	21.3% (33)
Total	100.0% (155)

<sup>1</sup> Sums to more than 100% because caregivers could indicate more than one health condition.

<sup>2</sup> Sums to more than 100% because more than one diagnosis could be selected.

APPENDIX G - *Hawaii Dementia Caregiver Survey*

**Table G.8. Doctor's Diagnosis of Care Recipient**

Live(d) with Care Recipient	Percent of Caregivers (Number)
Yes	56.8% (88)
No	34.2% (53)
Missing	9.0% (14)
Total	100.0% (155)

**Table G.9. Hours per Week Provided by Caregiver**

Caregiving Hours per Week	Percent of Caregivers (Number)
8 or less	12.3% (19)
9 – 19	7.1% (11)
20 – 39	13.5% (21)
40 or more	45.8% (71)
Missing	21.3% (33)
Total	100.0% (155)

**Table G.10. How Long Provided Care**

How Long Provide(d) Care	Percent of Caregivers (Number)
0 – 3 months	3.2% (5)
4 – 12 months	10.3% (16)
13 – 24 months	7.7% (12)
25 – 60 months	28.4% (44)
More than 60 months	29.7% (46)
Missing	20.6% (32)
Total	100.0% (123)

**Table G.11. Level of Consistent Help with Caregiving**

Level of Consistent Help with Caregiving <sup>3</sup>	Percent of Caregivers (Number)
Low (0 -2)	20.0% (31)
Somewhat low (3 – 4)	7.7% (12)
Moderate (5 – 6)	10.3% (16)
Somewhat high (7 – 8)	13.5% (21)
High (9 -10)	15.5% (24)
Missing	32.9% (51)
Total	100.0% (155)

<sup>3</sup> A 0 to 10 scale was used to measure consistent support, where 0 is low consistent support and 10 is high consistent support

## APPENDIX G - *Hawaii Dementia Caregiver Survey*

**Table G.12. *Reasons for Level of Consistent Help with Caregiving***

Reasons	Percent of All Respondents (Number)
Supportive family member (caregiver role sharing)	27.1% (42)
Hired paid caregiver	11.6% (18)
Only caregiver	8.4% (13)
Using long-term care services	2.3% (4)
Staying at institutional care	1.3% (2)
Help from staff at the living place	0.6% (1)

**Table G.13. *Responsibilities/Consequences of Caregiving***

Responsibilities/Consequences	Percent of All Respondents <sup>4</sup> (Number)
Does your care recipient need help with basic tasks such as housework, finances, or transportation?	79.4% (123)
Are you willing to have services in your care recipient's home (or your home)?	72.9% (113)
Does your care recipient need help with personal care such as hygiene, feeding, and dressing?	61.3% (95)
Do you currently have paid employment?	44.5% (69)
Do you have to awaken at night to help your care recipient?	41.3% (64)
Have you had to reduce your work hours, or have you had to take time off, to be a caregiver?	35.5%(55)
Have you had to quit your job to be a caregiver?	10.3% (16)
Are you receiving payment for your caregiving services?	9.7% (15)

**Table G.14. *Important Factors When Considering Family Caregiver's Needs***

Important Factors	Percent of All Respondents (Number)
Respite care availability	15.5% (24)
Support from family & neighborhood	13.5% (21)
Quality of service (humanitarian service)	8.4% (13)
Resources availability (money & time)	7.1% (11)
Access to service (easy access)	5.8% (9)
Sharing information & access to information	1.9% (3)
Independent living at home	1.9% (3)

<sup>4</sup> Sums to more than 100 percent because more than one response item could be selected.

APPENDIX G - *Hawaii Dementia Caregiver Survey*

**Table G.15. Important Care Recipient and Caregiver Services**

Services	Percent of All Respondents (Number)
Home-based respite services (formal care is provided to your care recipient while the caregiver has a temporary break)	20.0% (31)
Personal care services (bathing, dressing, toileting)	19.4% (30)
Information about Hawaii caregiver resources, services, tips	16.1% (25)
Homemaker services (house cleaning, shopping, errands)	16.1% (25)
Transportation to medical appointments, etc.	15.5% (24)
Case management (information, referral, care planning services)	14.2% (22)
Day care or day health services (outside the home)	13.5% (21)
Support groups	11.0% (17)
Training on stages of dementia, including difficult behaviors	11.0% (17)
Home-delivered meals	8.4% (13)
Training on stress management and coping skills	8.4% (13)
Hospice and end-of-life information and services	7.1% (11)
Mentor to call upon for caregiving issues	6.5% (10)
Financial counseling or management	6.5% (10)
Help completing an advanced health directive	5.2% (8)
Visits from a massage therapist (relaxation focused)	3.9% (6)
Family mediation or family therapy	2.6% (4)
Individual and confidential counseling	2.6% (4)
Spiritual counseling	1.9% (3)
Alternative therapies and expression (art, poetry, and journaling)	1.3% (2)
Learning how to advocate for laws about caregiver issues	0.6% (1)

**Table G.16. Use of Care Recipient Services**

Care Recipient Services	Use of Care Recipient Services (Percent of All Respondents)		
	Used	Have Not Used	
		Would Like to Use	Do Not Want to Use
Help completing an advanced healthcare directive	36.8% (57)	9.0% (14)	27.1% (42)
Case management (information, referral, care planning services)	34.2% (53)	21.9% (34)	17.4% (27)
Personal care services (bathing, dressing, toileting)	32.9% (51)	16.1% (25)	27.7% (43)
Day care or day health services (outside the home)	29.7% (46)	25.2% (39)	21.9% (34)
Homemaker services (house cleaning, shopping, errands)	29.7% (46)	23.9% (37)	27.1% (42)
Transportation to medical appointments, etc.	27.7% (43)	16.8% (26)	31.6% (49)
Home-delivered meals	14.8% (23)	20.6% (32)	40.0% (62)

Total respondents = 155

APPENDIX G - *Hawaii Dementia Caregiver Survey*

**Table G.17. Use of Caregiver Services**

Caregiver Services	Percent of All Respondents (Number)		
	Used	Have Not Used	
		Would Like to Use	Do Not Want to Use
Information about Hawaii caregiver resources, services, tips	41.3% (64)	23.9% (37)	9.0% (14)
Home-based respite services (formal care is provided to your care recipient while caregiver has a temporary break)	27.1% (42)	26.5% (41)	18.1% (28)
Support groups	26.5% (41)	23.9% (37)	21.9% (34)
Training on stages of dementia, including difficult behaviors	25.2% (39)	36.8% (57)	13.5% (21)
Hospice and end-of-life information and services	24.5% (38)	27.7% (43)	18.1% (28)
Legal services	23.9% (37)	22.6% (35)	25.2% (39)
Training on stress management and coping skills	20.6% (32)	28.4% (44)	23.2% (36)
Spiritual counseling	20.0% (31)	12.3% (19)	35.5% (55)
Someone to help with your nutrition/exercise	18.7% (29)	21.9% (34)	30.3% (47)
Visits from a massage therapist (relaxation-focused)	16.8% (26)	34.2% (53)	21.3% (33)
Alternative therapies and expression (art, poetry and journaling)	16.8% (26)	21.3% (33)	30.3% (47)
Individual and confidential counseling	15.5% (24)	21.9% (34)	31.0% (48)
Grief and bereavement services	14.8% (23)	18.1% (28)	32.3% (50)
Financial counseling or management	14.2% (22)	21.3% (33)	34.8% (54)
Mentor to call upon for caregiving issues	14.2% (22)	34.2% (53)	21.9% (34)
Learning how to advocate for laws about caregiver issues	11.0% (17)	28.4% (44)	26.5% (41)
Family mediation or family therapy	8.4% (13)	24.5% (38)	36.8% (57)

Total respondents = 155

<sup>5</sup> Sums to more than 100 percent since more than one service could be selected.

**A SURVEY FOR CAREGIVERS OF SOMEONE WITH MEMORY LOSS OR DEMENTIA**

If you currently, or formerly, provide(d) care for an older adult with memory impairment in your home, their home, or long-distance -- **you are a caregiver and we need your help.**

Many people provide informal care for little or no pay, due to family bonds, friendship, or love.

The Hawaii State Executive Office on Aging, in partnership with the Alzheimer's Association, Aloha Chapter, has formed a special State Task Force on **Alzheimer's Disease and Related Dementias (ADRD)**. Our goal is to improve the lives of people with ADRD and their caregivers. Your opinions in this anonymous survey will help us assess the current and future impact of ADRD on Hawaii's residents. Thank you for your help. Any questions? Call (808) 586-0100.

**Please feel free to complete the survey at your convenience and mail it to us. Our address is:**

Executive Office on Aging, Attention: ADRD Task Force  
250 South Hotel Street, Suite 406, Honolulu, Hawaii 96813-2831

Fill in the blanks to complete this survey. **If you are a former caregiver, please answer based on past caregiving experience.**

About you	About the person you're providing care to (care recipient)
How old are you? _____	How old is (or was) your care recipient? _____
Are you? Male <input type="checkbox"/> Female <input type="checkbox"/>	What best describes your relationship to your care recipient? Spouse/Partner <input type="checkbox"/> Parent <input type="checkbox"/> Grandparent <input type="checkbox"/> Aunt/Uncle <input type="checkbox"/> Neighbor <input type="checkbox"/> Hanai Family <input type="checkbox"/>
What is your ethnicity? (Circle all that apply) Japanese <input type="checkbox"/> Hawaiian <input type="checkbox"/> Filipino <input type="checkbox"/> Caucasian <input type="checkbox"/> Korean <input type="checkbox"/> Chinese <input type="checkbox"/> Pacific Islander <input type="checkbox"/> African American <input type="checkbox"/> Other <input type="checkbox"/>	Other _____ Do you/did you live with the care recipient? Yes _____ No _____
How would you rate your health? (circle one) Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Excellent <input type="checkbox"/>	<b>With regard to caregiving</b>
What health conditions do you have? High blood pressure <input type="checkbox"/> Heart Disease <input type="checkbox"/> Diabetes <input type="checkbox"/> Other <input type="checkbox"/> None <input type="checkbox"/>	How many hours do/did you spend each week? _____ Are you a former or current caregiver? _____ Approximately how long have you provided care? _____ How much money do/did you spend each month on care? _____
On a scale of 1-10 (1=low, 10=high) what was your stress level over the past month? _____	On a scale of 0 to 10 (1=low, 10=high), how much consistent help do you get with your caregiving responsibilities? _____
Zip Code _____	Please explain: _____ _____
<b>What diagnosis did your care recipient's doctor provide?</b>	
Alzheimer's Disease _____ Other dementia _____ Mild Cognitive Impairment (MCI) _____ Other (explain) _____	

Does your care recipient need help with personal care such as hygiene, feeding, and dressing?	Yes	No
Does your care recipient need help with basic tasks such as housework, finances, or transportation?	Yes	No
Do you have to awaken at night to help your care recipient?	Yes	No
Have you had to quit your job to be a caregiver?	Yes	No
Do you currently have paid employment?	Yes	No
Have you had to reduce your work hours, or have you had to take time off, to be a caregiver?	Yes	No
Are you receiving payment for your caregiving services?	Yes	No
Are you willing to have services within your care recipient's home (or your home)?	Yes	No

**Please share what you think is important for us to know when considering the needs of family caregivers.** (For example: What are the positive aspects of caregiving? Do you have enough support? What do you wish were different?)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

<p><i>The following list contains services some caregivers use to help them support their care recipients.</i></p> <p><b><u>Please indicate your preference for use:</u></b></p> <p><i>Use: past or present</i></p> <p><i>Do not use: would like to or don't want it</i></p> <p><i>Unable to use: explain why.</i></p>	Use	Do not use		<p><b>Unable to use</b></p> <p><b>Explain barrier</b></p> <p><small>(E.g. No time to arrange, can't afford the service, resistance from care recipient, or other barrier)</small></p>
	Past or present	Would like to	Don't want it	
<b>Care recipient services</b>				
<input type="checkbox"/> Transportation to medical appointments, etc.				
<input type="checkbox"/> Homemaker services (house cleaning, shopping, errands)				
<input type="checkbox"/> Personal care services (bathing, dressing, toileting)				
<input type="checkbox"/> Home-delivered meals				
<input type="checkbox"/> Case management (information, referral, care planning services)				
<input type="checkbox"/> Day care or day health services (outside the home)				
<input type="checkbox"/> Help completing an advanced healthcare directive				
<b>Caregiver services</b>				
<input type="checkbox"/> Home-based respite services (formal care is provided to your care recipient while the caregiver has a temporary break)				
<input type="checkbox"/> Information about Hawaii caregiver resources, services, tips				
<input type="checkbox"/> Support groups				
<input type="checkbox"/> Family mediation or family therapy				
<input type="checkbox"/> Individual and confidential counseling				
<input type="checkbox"/> Mentor to call upon for caregiving issues				
<input type="checkbox"/> Alternative therapies and expression (art, poetry and journaling)				
<input type="checkbox"/> Training on stress management and coping skills				
<input type="checkbox"/> Training on stages of dementia, including difficult behaviors				
<input type="checkbox"/> Hospice and end-of-life information and services				
<input type="checkbox"/> Someone to help with your nutrition/ exercise				
<input type="checkbox"/> Grief and bereavement services				
<input type="checkbox"/> Spiritual counseling				
<input type="checkbox"/> Visits from a massage therapist (relaxation-focused)				
<input type="checkbox"/> Financial counseling or management				
<input type="checkbox"/> Legal services				
<input type="checkbox"/> Learning how to advocate for laws about caregiver issues				
<b><i>Please check the boxes in front of your 5 MOST IMPORTANT service choices on the list above.</i></b>				

**Do you have anything else you'd like to share with the Task Force that could help us help you?**

**Thank you for taking the time to complete this survey!**

**OPTIONAL:** Please indicate if you would like to receive caregiving news or information, or might be willing to assist the State Task Force on ADRD in the future.  Would like news & information.

Yes! I am willing to help in future studies and focus groups.  No. I am not able to participate further.



State of Hawaii  
Executive Office on Aging

**OPTIONAL:**

Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Contact Number: \_\_\_\_\_  
E-Mail: \_\_\_\_\_

alzheimer's association  
Aloha Chapter



## APPENDIX H - 2011 Behavioral Risk Factor Surveillance System (BRFSS) Cognitive Impairment Module

In 2011, Hawaii was one of 22 states to administer the BRFSS cognitive impairment module. BRFSS is a state-specific, random-digit dial telephone survey that uses a weighting methodology to improve the representativeness of survey estimates. The module consists of ten questions on cognitive impairment among adults in the household. Cognitive impairment is defined as the worsening of confusion or memory loss in the past 12 months. The tables in this appendix show the presence and effects of cognitive impairment in the households in Hawaii. Section A shows the demographic characteristics of the cognitively impaired survey respondents, in particular those 60 and older, and Section B shows the effects on households. Both are provided since, as Table G.3 shows, approximately half of the households with a cognitively impaired adult had a survey respondent who happened not to be cognitively impaired.

The results in Section A show the risk of cognitive impairment increasing with age. The rate of cognitive impairment among respondents age 60 and older was 9.2 percent compared to 5.7 percent for those under age 60. (See Table H.1.) Also, as Table H.2 shows, the rate of cognitive impairment rose steadily from age group 60 to 64 to age group 75 to 84, but then fell in the 85 and older age group. Both genders appear to be equally at risk of being cognitively impaired.

Many households with a cognitively impaired adult reported the curtailment of routine activities by the person impaired. In nearly 40 percent of these households, the person impaired reduced their household, social, and employment activities during the course of the year. (See Tables H.4 and H.5.) In addition, 35 percent needed assistance from family members or friends during the past 30 days. (See Table H.6.) As Table H.7 shows, there was no one dominant need that these household shared.

The household results further show that most of the households have not sought medical attention for the impairment the household member was experience and, if they had, only about half were receiving treatment and an even smaller portion had been diagnosed.

APPENDIX H - 2011 Behavioral Risk Factor Surveillance System (BRFSS)  
Cognitive Impairment Module

**A. Respondent Results**

**Table H.1. Hawaii Respondents Reporting Memory Loss or Confusion**

Age Group	Respondent	
	Number	Percent of Population
Under Age 60	41,939	5.7%
Age 60 and Over	24,489	9.2%
Total	66,428	14.9%

<sup>1</sup>Weighted for Adult Hawaii Population

**Table H.2. Hawaii Respondents Age 60 and Older who Recently Experienced Confusion or Memory Loss**

Characteristics	Percent with Confusion/Memory Loss
<b>Age</b>	
Age 60 to 64	6.3%
Age 65 to 74	8.3%
Age 75 to 84	13.7%
Age 85+	9.4%
<b>Gender</b>	
Male	9.3%
Female	9.2%
<b>Education Attainment</b>	
Less than High School	8.2%
High School	11.1%
Some College	8.1%
College Graduate	9.3%

Note. From data from the 2011 Hawaii Behavioral Risk Factor Surveillance System (BRFSS).

<sup>6</sup> Weighted for adult Hawaii population

APPENDIX H - 2011 Behavioral Risk Factor Surveillance System (BRFSS)  
Cognitive Impairment Module

**B. Household Results**

**Table H.3.** Questions 1 and 2: During the past 12 months, did you or another adult 18 or older in your household experienced confusion or memory loss that is happening more often or is getting worse?

Households with Cognitively Impaired Resident(s)	Percent
No cognitively impaired resident(s)	86.1%
Cognitively impaired resident(s)	13.9%
a. Cognitively impaired respondent living alone	3.2%
b. Cognitively impaired respondent living with other cognitively impaired adult household member(s)	2.8%
c. Non-cognitively impaired respondent living with cognitively impaired adult(s)	8.1%
Total	100.0% (414,896)

**Table H.4.** Question 4: During the past 12 months, how often have you (has this person) given up household activities or chores you (they) used to do because of confusion or memory loss that is happening more often or is getting worse?

Households with at Least One Cognitively Impaired Member	Percent
Always, usually, or sometimes	37.9%
Rarely or never	60.5%
Unknown	1.5%
Total	99.9%

**Table H.3.** Question 6: During the past 12 months, how often has confusion or memory loss interfered with your (this person's) ability to work, volunteer, or engage in social activities?

Households with at Least One Cognitively Impaired Member	Percent
Always, usually, or sometimes	37.1%
Rarely or never	61.3%
Unknown	1.6%
Total	100.0%

**Table H.4.** Question 7: During the past 30 days, how often has a family member or friend (have you) provided any care or assistance for you (this person) because of confusion or memory loss?

Households with at Least One Cognitively Impaired Member	Percent
Always, usually, or sometimes	35.4%
Rarely or never	63.5%
Unknown	1.1%
Total	100.0%

<sup>7</sup> Results weighted by households

APPENDIX H - 2011 Behavioral Risk Factor Surveillance System (BRFSS)  
Cognitive Impairment Module

**Table H.5.** Question 5: As a result of your (this person's) confusion or memory loss, in which of the following four areas do you (does this person) need the MOST assistance?

Households with at Least One Cognitively Impaired Member	Percent
Transportation	17.2%
Household activities	13.8%
Personal care	10.2%
Safety	9.1%
Other assistance	3.1%
No assistance needed	41.6%
Unknown	2.5%
Total	100.0%

**Table H.6.** Question 8: Has anyone discussed with a health care professional increases in your (this person's) confusion or memory loss?

Households with at Least One Cognitively Impaired Member	Percent
Yes	34.1%
No	63.9%
Unknown	2.1%
Total	100.0%

**Table H.7.** Question 9: Have you (Has this person) received treatment such as therapy or medications for confusion or memory loss?

Households with at Least One Cognitively Impaired Member	Percent
Yes	16.0%
No	17.7%
Unknown	0.4%
Not discussed	65.9%
Total	100.0%

**Table H.8.** Question 10: Has a health care professional ever said that you have (this person has) Alzheimer's disease or some other form of dementia?

Households with at Least One Cognitively Impaired Member	Percent
Alzheimer's disease	3.5%
Other form of dementia	6.4%
No diagnosis	23.6%
Unknown	0.6%
Not discussed with health care professional	65.9%
Total	100.0%

## Behavioral Risk Factor Surveillance System Optional Impact of Cognitive Impairment Module

Introduction: The next few questions ask about difficulties in thinking or remembering that can make a big difference in everyday activities. This does not refer to occasionally forgetting your keys or the name of someone you recently met. This refers to things like confusion or memory loss that are happening more often or getting worse. We want to know how these difficulties impact you or someone in your household.

1. During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse? \*  

(1) Yes	(2) No
---------	--------
2. How many adults 18 years or older in your household experienced confusion or memory loss that is happening more often or is getting worse during the past 12 months?
3. Of these people, please select the person who had the most recent birthday. How old is this person?
4. During the past 12 months, how often have you/ has this person given up household activities or chores you/ they used to do, because of confusion or memory loss that is happening more often or is getting worse?  

(1) Always	(4) Rarely
(2) Usually	(5) Never
(3) Sometimes	
5. As a result of your/ this person's confusion or memory loss, in which of the following four areas do you/ does this person need the most assistance?  

(1) Safety	(5) Needs assistance, but not in those areas
(2) Transportation	(6) Doesn't need assistance in any area
(3) Household activities	
(4) Personal care	
6. During the past 12 months, how often has confusion or memory loss interfered with your/this person's ability to work, volunteer, or engage in social activities?  

(1) Always	(3) Sometimes
(2) Usually	(4) Rarely

APPENDIX H - 2011 Behavioral Risk Factor Surveillance System (BRFSS)  
Cognitive Impairment Module

(5) Never

7. During the past 30 days, how often has a family member or friend provided any care or assistance for you/this person because of confusion or memory loss?

(1) Always

(2) Usually

(3) Sometimes

(4) Rarely

(5) Never

8. Has anyone discussed with a health care professional, increases in your/this person's confusion or memory loss?

(1) Yes

(2) No [End of module]

9. Have you/ Has this person received treatment such as therapy or medications for confusion or memory loss?

(1) Yes

(2) No

10. Has a health care professional ever said that you have/ this person has Alzheimer's disease or some other form of dementia?

(1) Yes, Alzheimer's Disease

(2) Yes, some other form of dementia but not Alzheimer's disease

(3) No diagnosis has been given

\*Note: This module is designed to ask questions #4-10 of the individual who answers the phone or a member of their household. The individual is asked the questions if he/she answers "yes" to question #1. If the individual answers "no" to question #1 then questions #4-10 are asked of a member of the household who is experiencing confusion or memory loss.

## APPENDIX I - American Community Survey, Special Tabulation on Aging

The American Community Survey (ACS) is an annual nationwide survey conducted by the United States Census Bureau. The ACS collects detailed information on population and housing characteristics, and on social and economic conditions.

Since 2008, the ACS survey asked respondents the following question on cognitive difficulty:

“Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?” The Bureau’s most recent three-year estimates showed the level of cognitive difficulty among Hawaii residents age 60 and older to be similar to the US population as a whole. It also showed cognitive difficulty increasing with age, rising to approximately 3 in 10 Hawaii residents age 85 and older experiencing cognitive difficulty, regardless of gender. It further showed the risk of cognitive difficulty to be similar for males and females.

**Table I.1. Percentage of the Population Age 60 and Older with Cognitive Difficulty**

	With Cognitive Difficulty	No Cognitive Difficulty
United States	8.2%	91.8%
Hawaii	8.9%	91.1%

Note. From the 2009-2011 American Community Survey, Special Tabulation on Aging prepared by the U.S. Census Bureau, 2013.

**Table I.2. Percentage of the Population with Cognitive Difficulty by Age Group and Gender**

GENDER	AGE GROUPS				
	Age 60+	Age 60-64	Age 65-74	Age 75-84	Age 85+
Female	9.2% (25,275)	4.4% (1,870)	5.5% (2,865)	12.4% (4,565)	30.4% (5,325)
Male	8.4% (10,650)	5.0% (2,105)	5.0% (2,375)	12.0% (3,130)	28.4% (3,040)

Note. From the 2009-2011 American Community Survey, Special Tabulation on Aging, prepared by the U.S. Census Bureau, 2013.

## APPENDIX J - Key Informant Survey and Results

A survey of key informants was conducted in August 2013. The survey consisted largely of open-ended question inquiring into the accessibility and quality of dementia care in the State of Hawaii. The key informants were selected on the basis of their knowledge and expertise in issues related to older adults and dementia care. A total of 59 key informants completed or partially completed the survey. The respondents had the option to remain anonymous. Only two respondents chose to remain anonymous.

The survey results are presented in the tables below. The tables show three dominant themes in the key informants' responses. One theme pertained to the high cost of dementia care, which prevented persons with dementia and their families from accessing services. Most of the respondents selected finances as the most important challenge related to dementia care. Three-quarters of the respondents answered affirmatively to the question on knowledge of someone who encountered financial challenges.

Another frequently mentioned theme was the preference for non-institutional care and, related to that, support for family caregivers. Caring for persons with dementia at home and providing support to the caregivers were the two most frequently mentioned strategies for providing dementia sufferers with high quality of life and care. The latter was the second most frequently mentioned most important challenge that persons with dementia and their caregivers faced.

The third common theme was the lack of services and skilled professionals. Limited services or resources, and lack of trained professionals were the second and third most frequently mentioned responses to barriers encountered by persons with dementia and their families. Only 2 of the respondents felt that there was enough adequately trained dementia care professionals in the state and 32 of the respondents had problems related to diagnosis or treatment. Medical or healthcare was the third most frequently mentioned most important challenge. Quality treatment services were also considered by many to be important in providing persons with dementia a good quality of life and care.

**Table J.1. Question 4: In your opinion, what is the best Quality of Life and Care for someone with dementia?**

Best Quality of Life	Number
Stay in the home	15
Social supports (engaged in family and the community)	11
Quality treatment services	10
Safe and comfortable environment	8
Quality hospice and residential care	6
Independence	4
Screening and diagnosis	2
Financial resources	2
Advanced health care directive	1
No opinion/don't know	3



## APPENDIX J - Key Informant Survey and Results

**Table J.2.** *Question 5: In your knowledge and experience, are there areas of excellence for dementia care in Hawaii?*

Areas of Excellence in Hawaii	Number
Physicians	4
Adult day care	4
Social workers	3
Nurses	2
Hale Makua	2
UH School of Medicine	2
Chris Ridley	2
Castle Hospital	1
Hawaii Island Adult Care Inc	1
Don't know	13

**Table J.3.** *Question 6: What are the barriers for someone with dementia (or their families) in our state?*

Barriers in Dementia Care in Hawaii	Number
Cost of care	19
Limited services/Resources	17
Lack of trained professionals	8
Education	6
Respite care	5
Accessibility to reliable information	3
Stigma of dementia	3
No research	2
End-of-life planning	2

**Table J.4.** *Question 8: Where are the most effective places that you think the general public should receive public awareness messages about dementia or memory loss?*

Effective Modes for Public Awareness Messages	Number
Television	34
Doctor's office	34
Senior center	32
Radio	27
Newspaper	26
Workplace	21

**Table J.5.** *Question 9: Have you experienced problems related to dementia diagnosis or treatment of dementia by doctors, nurses, or other healthcare professionals? This can include services in hospitals, emergency rooms, hospice facilities, skilled nursing & rehabilitation facilities, community health centers, or outpatient services.*

Had Problems in Care Provided by Healthcare Professionals	Number
Yes	32
No	17

## APPENDIX J - Key Informant Survey and Results

**Table J.6. Question 10: Please explain the problems you have experienced (related to dementia diagnosis or treatment of dementia by doctors, nurses, or other healthcare professionals).**

Problems in Care Provided by Healthcare Professionals	Number
Lack of trained medical professionals	14
Inadequate effective treatment services	6
Cost to caregivers	4
Insufficient diagnostic criteria	4
Lack of resources	3
Education on dementia	2
Lack of safety planning (poor discharge planning)	2
Caregiver resources	1
Inappropriate use of antipsychotic medication	1
Not applicable	1

**Table J.7. Question 12: Have you or anyone you know had legal challenges relative to someone's diagnosis of dementia or cognitive impairment?**

Had Legal Challenges	Number
Yes	30
No	20

**Table J.8. Question 13: What could be improved involving access to legal services for those with dementia, their families and their caregivers?**

Improving Access to Legal Services	Number
Advanced Health Care Directive/Durable Power of Attorney	12
Access to lawyers	8
Awareness and education	7
Resources	3
Protection from fraud	2
More ombudsman	2
In-home legal services	1
Punishment	1
Don't know	3

**Table J.9. Question 14: Is it easy for someone with dementia and their family to access services?**

Easy to Access Dementia Care Services	Number
Yes	7
No	41

## APPENDIX J - Key Informant Survey and Results

**Table J.10.** *Question 15: Have you or someone you know had issues with transportation, safety, first responders, emergency services, housing, connecting to services, and/or residential options for someone with dementia?*

Dementia Care Issues Encountered	Number
Limited access to resources	11
Inadequate services	9
Lack of financial resources	2
Lack of cultural competence	1
Refusal to acknowledge dementia	1
Maui Adult Day Care	1
“Bundled” payment for hospital services	1
Difficult to transfer hospitals	1
Transportation to adult day care	1
No issue/don’t know	3

**Table J.11.** *Question 16: Have you or anyone you know been challenged by financial issues involving someone with memory loss or dementia?*

Encountered Financial Challenges	Number
Yes	37
No	12

**Table J.12.** *Question 17: Please explain the financial issues. What could be improved for people with memory loss in relation to the cost of long-term care? This would include financial challenges of the family and caregivers.*

Financial Care Issues Related to Dementia Care	Number
Health care too expensive	16
Financial resources	7
Long-term care insurance	5
Scams/Fraud	5
Medicaid	2
Lack of options	2
Tuition assistance for day care	2
Insurance needs to cover more	1
Medication	1
Referral to resources	1

## APPENDIX J - Key Informant Survey and Results

**Table J.13. Question 18: What are the barriers to better support of family caregivers of someone with dementia?**

Barrier to Support of Family Caregivers	Number
Finances	13
Lack of knowledge on dementia	10
Caregiver burnout	8
Lack of respite	7
Lack of knowledge on available resources	7
Lack of caregiver training	6
Lack of family help	6
Caregiver not asking for help	4
Caregiver is employed	4
Family dynamics	3

**Table J.14. Question 19: What services would you like to see more of for family caregivers?**

Desired Services for Family Caregivers	Number
Respite	18
Caregiver support group	10
Caregiver training	6
Dementia education	6
Online support	4
Referral services	4
Adult Day Care	4
Case management	3
Financial/legal services	3
Medical support	3

**Table J.15. Question 20: What are the barriers to desired services?**

Barriers to Services Desired for Family Caregivers	Number
Cost of services	23
Lack of knowledge of available resources	8
Lack of services	7
Poor access	6
Lack of training	6
Funding	4
Caregiver does not ask for help	4
Stigma/stereotype	3
Lack of time for services	2
Cultural barriers	2

**Table J.16. Question 21: Do you feel that there are enough adequately trained/skilled professionals for dementia care in Hawaii? (This can include doctors, nurses, paraprofessionals like certified nurse's assistants, physical therapists, speech therapists, physical therapists).**

Sufficient Number of Skilled Dementia Care Professionals in Hawaii	Number
Yes	2
No	42

## APPENDIX J - Key Informant Survey and Results

**Table J.17. Question 22: What are the barriers to having a workforce that is trained or skilled in dementia care?**

Barriers to Skilled Dementia Care Workforce	Number
Low wages	13
Lack of interest geriatric careers among youth	6
Lack of education	6
Cost of training	5
Lack of jobs	3
Difficult field emotionally	3
Insurance barriers	2

**Question 23. How would you suggest improving the workforce?**

Suggestions for Improving Workforce	Number
Better wages	10
Training	7
Education—more course offerings and encouragement for students to pursue careers in geriatric care	5
Fund education	3
Focus on skills	3
Incentives (to attract professionals to the state?)	2
Online support	2
Hire abroad	1
Cultural competence	1
Healthcare workforce development center	1

**Question 25. What could be improved or what works in these settings for people with memory loss?**

Suggestions for Improving Dementia Care Settings	Number
Familiar surroundings (personal items)	5
Caring workers	5
Appropriate activities	5
Better training	4
Adequate staff	4
Family support	3
Patient center	3
Structure	2

**Question 26. Describe your experience with access to services in the home, like affordability, or availability, or quality of care.**

Experience with Home Services	Number
Cost	11
Limited services	7
Quality of care	4
Limited access of services	3
Insurance coverage	3
Training	2
Unknown available resources	1
Need ADA	1

## APPENDIX J - Key Informant Survey and Results

**Question 27.** *How could these home services be improved for people with memory loss and their caregivers?*

Suggestions for Improving Home Services	Number
Address cost issue	7
Better supervision	4
Respite care	4
Training	3
Community of resources	2
Better wages	2
Education	1
Home delivery services	1

**Question 28.** *Please rank the potential challenges in terms of their importance in addressing the needs of individuals with dementia and their caregivers. (using number 1 as most important and 7 as least important)*

Potential Challenges	Most Important (Number)
Financial	11
Support for family or unpaid caregivers	10
Medical/healthcare	9
Public awareness	5
Sufficient workforce trained in dementia issues	4
Legal	2
Infrastructure	2

**Question 29:** *Do you have ideas for how the state and communities can be involved in supporting individuals with dementia or cognitive impairment, their families and their caregivers?*

Involving State and Community in Supporting Persons with Dementia and their Families	Number
Funding	6
Information center	5
Education	5
Public awareness	5
State plan	4
Support for agencies	4
Volunteer groups	3
Respite	3
Training	2
Insurance barriers	1

Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

---

**HAWAII STATE PLAN ON ALZHEIMER'S DISEASE AND RELATED DEMENTIAS  
(ADRD)**

**KEY INFORMANT SURVEY**



**Vision:** We are committed to embrace and support with Aloha, all of Hawaii's people who are touched by Alzheimer's Disease and Related Dementias, from early detection to end of life, always keeping alive the hope of prevention and eventual cure, and aiming for the best quality of life for all.

The Hawaii Executive Office is conducting this survey to gather important information from key stakeholders in the community on the importance of issues related to Alzheimer's Disease & related dementias (ADRD). We appreciate your time, expertise and willingness to share your thoughts and suggestions with us as we forge Hawaii's first state plan to address ADRD. It has become crucial to be prepared for our rapidly aging population by understanding the barriers and good practices related to dementia care and research. We are using the term "dementia" to refer to any form of memory loss or cognitive decline.

**PLEASE DO NOT FORWARD OR SHARE THIS SURVEY, BECAUSE YOU HAVE BEEN IDENTIFIED PERSONALLY AS SOMEONE FROM WHICH WE WOULD LIKE TO RECEIVE FEEDBACK.**

Please complete the survey by August 26. We will keep your contact information confidential, but a list of the names of participants of our workgroups and key informants will be included in the final report to the 2014 Legislature.

If you have questions about this survey, please contact Jody Mishan at 586-7317 or [Jody.Mishan@doh.hawaii.gov](mailto:Jody.Mishan@doh.hawaii.gov)

Send this completed survey to:

Jody Mishan  
Coordinator, Alzheimer's Disease and Related Dementias  
Executive Office on Aging  
250 South Hotel Street, #406  
Honolulu, HI 96813  
Fax: (808) 586-0185

Or, email it as an attachment to:  
[Jody.Mishan@doh.hawaii.gov](mailto:Jody.Mishan@doh.hawaii.gov)

Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

**PROFILE**

<b>1. Name and contact information</b>	
a.	Name
b.	Company
c.	Position:
d.	Professional title/s (MD, PhD, etc.)
e.	Preferred mailing address
f.	Address 2
g.	City/Town
h.	State
j.	Zip code
g.	Preferred contact e-mail
h.	Preferred contact phone number
<b>2. Are you willing to be part of a growing "dementia coalition" in Hawaii, and receive dementia-related news and information?</b>	
	Yes _____
	No _____

**GLOBAL/OVERALL QUESTIONS**

*We would like to learn what your hopes are for the state plan and your impressions of dementia care in Hawaii*

**3. What would your wishes be for the first State Plan on Alzheimer's Disease & Related Dementias (ADRD)? (Your hopes for improving dementia care in Hawaii)**



Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

---

**4. In your opinion, what is the best Quality of Life and Care for someone with dementia?**

**5. In your knowledge or experience, are there areas of excellence for dementia care in Hawaii? Please describe.**

**6. What are the barriers for someone with dementia (or their families and caregivers) in our state?**

Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

**PUBLIC AWARENESS AND EDUCATION**

*The next two questions ask about your impression of the information on ADRD available to residents of Hawaii*

<b>7. Do you feel there is sufficient public information or education/training about Alzheimer's and dementia?</b>	<b>Yes</b> _____
	<b>No</b> _____

<b>8. Where are the most effective places that you think the general public should receive public awareness messages about dementia or memory loss? Please check all that apply.</b>		
Radio _____	TV _____	Newspaper _____
Doctor's office _____	Senior Center _____	Workplace _____
Others (Indicate): _____		

**CHALLENGES FOR PERSONS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS**

*Persons with Alzheimer's disease or other related dementias and their caregivers may face a number of challenges. These challenges may be medical, legal, infrastructural, financial, family or unpaid caregiver related, and/or finding professionals skilled or trained in dementia care. In the following sections, we will ask you questions on these potential challenges.*

Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

---

**MEDICAL CARE CHALLENGES**

*The first set of questions inquire about your impression of the medical care available in Hawaii for patients with Alzheimer's disease and related dementias and your recommendations for improvements.*

<b>9. Have you experienced problems related to dementia diagnosis or treatment of dementia by doctors, nurses, or other healthcare professionals? This can include services in hospitals, emergency rooms, hospice facilities, skilled nursing &amp; rehabilitation facilities, community health centers, or outpatient services</b>	<b>Yes</b> _____ <b>No</b> _____
--	-------------------------------------

**10. Please explain the problems you experienced. What are your suggestions to improve medical care of persons with dementia in these locations?**

**11. If you have anything to share about excellent medical dementia care or practices, please describe where this occurred and why you found it to be optimal care.**

Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

**LEGAL CHALLENGES**

*Next, we would like to get your impression of the legal challenges faced by persons with dementia and their families in Hawaii.*

<b>12. Have you or anyone you know had legal challenges relative to someone's diagnosis of dementia or cognitive impairment?</b>	Yes _____ No _____
--	-----------------------

**13. What could be improved involving access to legal services for those with dementia, their families and their caregivers?**

**INFRASTRUCTURE CHALLENGES**

*In this section, we ask about issues related to the availability of facilities, services, and transportation for persons with Alzheimer's disease and related dementias.*

<b>14. Is it easy for someone with dementia and their family to access services?</b>	Yes _____ No _____
--	-----------------------

**15. Have you or someone you know had issues with transportation, safety, first responders, emergency services, housing, connecting to services, and/or residential options for someone with dementia? Please explain.**

Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

**FINANCIAL CHALLENGES**

*We would now like to ask you about possible financial challenges faced by persons with dementia, their families and their caregivers.*

**16. Have you or anyone you know been challenged by financial issues involving someone with memory loss or dementia?**

Yes \_\_\_\_\_

No \_\_\_\_\_

**17. Please explain the financial issues. What could be improved for people with memory loss in relation to the cost of long-term care? This would include financial challenges of the family and caregiver/s.**

**FAMILY OR UNPAID CAREGIVER CHALLENGES**

*Family or unpaid caregivers (also called "informal caregivers") of persons with dementia may face a number of challenges. We would like to get your impression of these challenges and the support they might need.*

**18. What are the barriers to better support of family caregivers of someone with dementia?**

Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

**19. What services would you like to see more of for family caregivers?**

--

**20. What are the barriers to desired services?**

--

**WORKFORCE CHALLENGES**

*We would also like to get your impression of the supply of health professionals that are qualified to care for persons with dementia or cognitive impairment and strategies for and/or barriers in addressing this issue.*

**21. Do you feel that there are enough adequately trained/skilled professionals for dementia care in Hawaii? (This can include doctors, nurses, paraprofessionals like certified nurse's assistants, physical therapists, speech therapists, physical therapists).**

Yes \_\_\_\_\_

No \_\_\_\_\_

**22. What are the barriers to having a workforce that is trained or skilled in dementia care?**

--

Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

---

**23. How would you suggest improving the workforce?**

**CARE SETTINGS FOR PERSONS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS**

*The final challenge we would like to receive your feedback on is the care provided in different care settings for individuals with dementia or cognitive impairment.*

**24. Have you had personal experience or have something to share about the following care settings, specifically in relation to dementia care. (Please check all that apply)**

<input type="checkbox"/>	Day care or day health	<input type="checkbox"/>	Emergency room
<input type="checkbox"/>	Care home	<input type="checkbox"/>	Hospice facility
<input type="checkbox"/>	Foster home	<input type="checkbox"/>	Hospital
<input type="checkbox"/>	Assisted living facility	<input type="checkbox"/>	Private home
<input type="checkbox"/>	Skilled nursing facility (SNF)	<input type="checkbox"/>	

**25. What could be improved or what works in these settings for people with memory loss?**

Hawai State Plan on Alzheimer’s Disease & Related Dementias (ADRD)

**26. Describe your experience with access to services in the home, like affordability, availability, or quality of care.**

**27. How could these home services be improved for people with memory loss and their caregiver/s?**

**RANKING THE POTENTIAL CHALLENGES FACED BY PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS**

**28. Please rank the potential challenges in terms of their importance in addressing the needs of individuals with dementia and their caregivers. (using number 1 as most important and 7 as least important)**

Medical/healthcare	
Legal	
Infrastructure (residential facilities, access to services, transportation, safety)	
Financial	
Support for family or unpaid caregivers	
Sufficient workforce trained in dementia issues	



Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

---

**STRATEGIES/RECOMMENDATIONS**

*In concluding this survey, we would like to get your recommendations or ideas for getting the residents and communities of Hawaii involved in dementia awareness, care, and strategies for improving the lives of people with cognitive impairment, their families and caregivers.*

**29. Do you have ideas for how the state and communities can be involved in supporting individuals with dementia or cognitive impairment, their families and their caregivers?**

**30. What specific recommendations do you have about how to better address any other issues with Alzheimer's Disease and related dementias? Please be as specific as possible about what you would like to see happen and why. If you'd like to add anything pertaining to excellent programs, services or practices for dementia care that you know about, please give details, indicating where or when. If there are particular professionals who you feel provide/d excellent dementia care, please share. (be specific)**

-END-

Hawai State Plan on Alzheimer's Disease & Related Dementias (ADRD)

---

Thank you so much for your time, experience, and expertise.  
Your feedback is of great value to the crafting of Hawaii's first state plan  
on Alzheimer's Disease & Related Dementias.

Mahalo!

If you wish to discuss this survey or have further questions or feedback, please  
contact:

[Jody.Mishan@doh.hawaii.gov](mailto:Jody.Mishan@doh.hawaii.gov)

Phone: (808) 586-7317

## References

- Alzheimer's Association. (2013a). *2013 Alzheimer's Disease Facts and Figures*. Retrieved from [http://www.alz.org/alzheimers\\_disease\\_facts\\_and\\_figures.asp](http://www.alz.org/alzheimers_disease_facts_and_figures.asp).
- Act on Alzheimer's. (n.d.). *Importance of Early Disease Detection*. Retrived in December 2013 from <http://www.actonalz.org/importance-of-early-detection>.
- Hawaii Health Information Corporation. (n.d.) Life expectancy at birth, Hawai'i vs. U.S. *Health Trends in Hawaii*. Retrieved in September 2013 from [http://healthtrends.org/status\\_life\\_expect.aspx](http://healthtrends.org/status_life_expect.aspx).
- Hawaii State Department of Business, Economic Development and Tourism. (2012, March). *Population and Economic Projections for the State of Hawaii to 2040*, DBEDT 2040 Series. Retrieved from <http://dbedt.hawaii.gov/economic/economic-forecast/2040-long-range-forecast/>.
- Hawaii Department of Health. 2011 Hawaii Behavioral Risk Factor Surveillance System (BRFSS).
- Hurd, M., Martorell, P., Delavande, A., Mullen, K., & Langa, K. (2013). Monetary costs of dementia in the United States. *The New England Journal of Medicine*, 368(14), 1325-1334.
- MetLife Mature Market Institute. (2012, November). *Market Survey of Long-Term Care Costs: The 2012 MetLife Market Survey of Nursing Homes, Assisted Living, Adult Day Care, and Home Care Costs*. New York: Author. Retrieved from <https://www.metlife.com/assets/cao/mmi/publications/studies/2012/studies/mmi-2012-market-survey-long-term-care-costs.pdf>.
- Minino, A. M., Arias, E., Kochanek, K. D., Murphy, S. L., & Smith, B. L. (2002, September 16). Deaths: final data for 2000. *National Vital Statistics Reports*. 50 (15), Hyattsville, Maryland: National Center for Health Statistics.
- Murphy, S. L., Xu, J. Q., & Kochanek, K.D. (2013, May 8). Deaths: final data for 2010. *National Vital Statistics Reports*, 61(4), Hyattsville, MD: National Center for Health Statistics.
- United States Census Bureau. (n.d.a). *2010 Demographic Profile Data*. Retrieve September 2013 from <http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>.
- U.S. Census Bureau. (n.d.). *2012 American Community Survey 1-Year Estimates, Population 65 Years and Older in the United States*. Retrieved in November 2013 from [http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_12\\_1YR\\_S0103&prodType=table](http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_12_1YR_S0103&prodType=table)



**Neil Abercrombie, Governor of Hawaii**

**Gary Gill, Acting Director of Health**

Published by

**Executive Office on Aging, Hawaii State Department of Health**

**Wesley Lum, PhD, MPH, Director**

December 2013

For more information, please contact the Executive Office on Aging at (808)586-0100

*Nondiscrimination in Services*

We provide access to our activities without regard to race, color, national origin (including language), age, sex, religion or disability.

Write or call our Affirmative Action Office at P.O. Box 3378, Honolulu, HI 96801-3378, or at (808)586-4616 within 180 days of the problem.