

**Hawai'i 2035**

# STATE STRATEGIC PLAN

**On Alzheimer's Disease & Related Dementias**

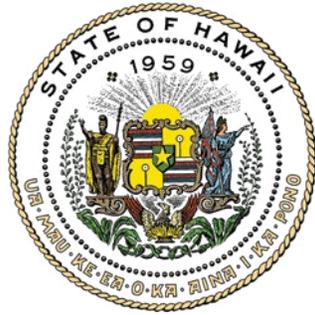


Hawai'i State Department of Health

Executive Office on Aging

September 2023





## Message from Josh Green, MD Office of the Governor, State of Hawai‘i

We are proud of the good work that our Executive Office on Aging, community partners and health professionals have contributed to produce the Hawai‘i 2035: State Strategic Plan on Alzheimer’s Disease and Related Dementias. This plan will guide the state as we work to address the issues related to Alzheimer’s disease and dementia.

As our older adult population continues to grow, we need to prepare the workforce, increase resources, and strengthen the support to our caregivers to meet the challenges and barriers this unfortunate disease presents. According to the Alzheimer’s Association 2023 Alzheimer’s Disease Facts and Figures report, in 2022, there were 60,000 caregivers in Hawai‘i providing 91 million hours of unpaid care to their loved one.

This equates to approximately \$1.9 billion of unpaid care. By 2025, the number of individuals living with Alzheimer’s disease is expected to increase to 35,000, and the cost of caring for individuals living with dementia will increase accordingly.

We are encouraged by the current research to find a cure for this disease, and we look forward to working with you to improve the quality of life for all of our ‘ohana.

Mahalo for all you do.

Aloha,



Josh Green, MD  
Governor, State of Hawai‘i





## Department of Health

### Kenneth S. Fink, MD, MGA, MPH

### Director, Ka Luna Ho'okele

The Hawai'i State Department of Health's mission is to promote and protect the physical, psychological, and environmental health of the people of Hawai'i through assessment, policy development, and assurance. Our vision is that all Hawai'i residents have a fair and just opportunity to achieve optimal health and well-being. Likewise, everyone deserves to live with the healthiest brain possible and to have the support needed to have quality of life while navigating the journey of Alzheimer's disease and related dementias.

Health is at the intersection of public health, healthcare, and human services. At the Department of Health, our work is central to creating a healthier Hawai'i today and for several generations to come. Brain health is an essential part of overall health because it affects every part of our body and directs our lives. Our brains constantly send and receive signals that control the major systems of our bodies. It is the essence of our personhood and what makes us alive.

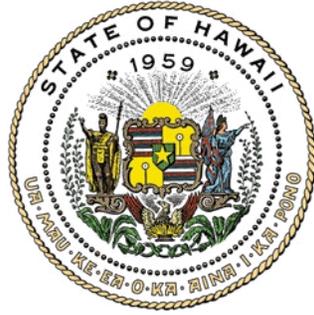


Alzheimer's disease is currently the 6th leading cause of death in Hawai'i; yet there is no cure to this devastating and progressive disease. It is the most under-recognized public health crisis in this day and age. However, we know more now than we ever have before. Chronic health conditions such as heart disease, diabetes, COPD, and stroke have been proven to increase the risk of cognitive decline. Meanwhile, healthy habits such as managing chronic health conditions, quitting smoking, exercising regularly, eating a balanced diet, and getting enough sleep have been proven to reduce the risk of developing dementia, improve cognitive function, and slow the rate of cognitive decline.

We must take action to not only prevent and reduce the risk of developing dementia in our state, but also to provide reliable guidance and vital support to those living with the diagnosis or caring for someone who is. The Executive Office on Aging and the coalition of community stakeholders are leading the way forward with this Hawai'i 2035: State Strategic Plan on Alzheimer's Disease and Related Dementias. It is imperative that our state collaboratively moves forward with this strategic plan to promote and protect the health of the people of Hawai'i.

Mahalo,

Kenneth S. Fink, MD, MGA, MPH  
Director of Health, Ka Luna Ho'okele



## Statement from the Director of the Executive Office on Aging

The Executive Office on Aging's vision is that Hawai'i is the best place to grow older; and the mission is to optimize the health, safety, and independence of Hawai'i's older adults and people with disabilities. We support our elders and their caregivers through planning, development, advocacy, and coordination of policies, programs, and services.

In 2013, we published a plan on Alzheimer's Disease and Related Dementias and in 2020 we received a grant from the Centers for Disease Control and Prevention to update our plan and align it with the Healthy Brain Initiative. This newly revised plan, Hawai'i 2035: State Strategic Plan on Alzheimer's Disease and Related Dementias, will focus on four public health domains, including: 1) Data; 2) Program and Policy; 3) Public Awareness and Education; and 4) Workforce Development. We partnered with Papa Ola Lōkahi to publish a Native Hawaiian Road Map which is also included in the State Plan. With the dedication and commitment of community stakeholders, these plans seek solutions to the public health challenges presented by Alzheimer's disease and related dementias in our state.

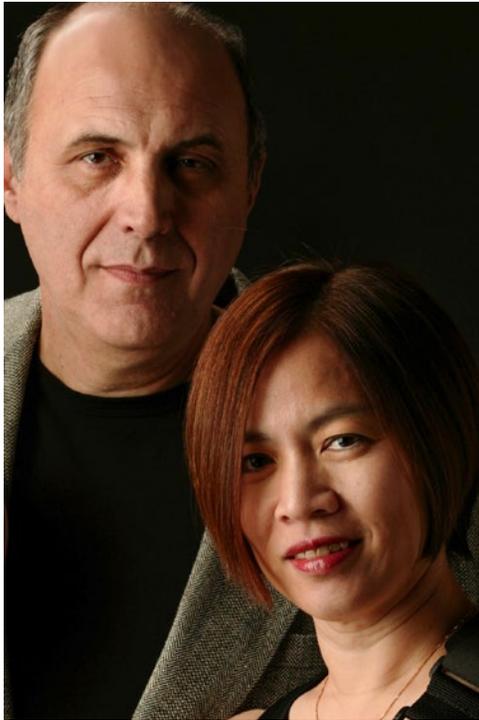


Alzheimer's disease is the most common type of dementia and is considered a progressive disease which worsens over time. While there is no cure, there is promising research being conducted in Hawai'i which gives us hope for the future. In 2020, of the state's 282,567 older adults, an estimated 29,000 elders (i.e., 65 years and older) are living with Alzheimer's disease and are being cared for by 60,000 family caregivers. These caregivers provide 91 million hours of unpaid care valued at more than \$1.9 billion and are a critical component of the long-term care support network for Hawai'i's multi-cultural elders. By 2025, the number of people living with Alzheimer's disease in Hawai'i is expected to rise to 35,000, a more than 20 percent increase from 2020. It is critical that we begin to address this issue now.

The Hawai'i 2035: State Strategic Plan on Alzheimer's Disease and Related Dementias is a "living document" that will evolve through further research, outreach, and engagement with community stakeholders, and will respect our diverse cultures with equity, inclusion, and aloha.

Mahalo,

Caroline Cadirao  
Director, Executive Office on Aging



Poem excerpt from the book titled  
*Missing*, written by Fred Fortin.  
The photograph depicts Fred and his  
dear wife, Dr. Betty Yee.

## Dementia

*It's a funny disease dementia.  
Like a thief it carries off your beloved,  
Then deceptively takes flight,  
Out of reach, out of sight into nowhere.  
The jewels are pawned first,  
History, future, everydayness,  
Never to be recovered.  
Never to be,  
Again.  
But the cruelty is not done yet.  
The real invasion comes  
When life itself is stolen,  
When life itself begins its retreat.  
When even God cannot find your beloved.  
When words only become tears.  
How can those left in the ashes,  
Robbed as they are,  
Forsaken as they are,  
Not have hearts that turn cold and gray?  
Where everyday objects are laden  
With tortured memories,  
Where grief is endless and barely endurable,  
And where time rolls over you, relentless.  
But hearts we have, still beating, still feeling.  
The great silence may be beckoning, but not yet.  
Inhale, breathe, soak it in.  
Open up to what has been clouded over and neglected.  
Regain your footing, give meaning to your trials,  
Find strength in love. It is still out there.  
And, in truth, the only way out.*

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# Mission



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



## EXECUTIVE SUMMARY

In October 2020, the Hawai‘i State Executive Office on Aging (EOA) received a 3-year planning grant from the Centers for Disease Control and Prevention (CDC) as part of its Building Our Largest Dementia Infrastructure (BOLD) Public Health Programs to Address Alzheimer’s Disease and Related Dementias (ADRD).

The planning grant enabled EOA to update the Hawai‘i 2025: State Plan on Alzheimer’s Disease and Related Dementias and align it with the CDC Healthy Brain Initiative 2018–2023 Roadmap. The updated state plan, Hawai‘i 2035: State Strategic Plan on Alzheimer’s Disease and Related Dementias, will be a blueprint to strengthen the capacity of our state agencies and community partners to build a strong infrastructure that will reduce the risk of cognitive decline, promote healthy brain development, and support caregivers who are caring for individuals with dementia. There are strategies and action items in four public health domains: 1) Data; 2) Program and Policy Change; 3) Public Awareness and Education; and 4) Workforce Development.

Consistent with the overarching goal to strive for diversity, equity, and inclusion in public health planning and programs, the Road Map for Native Hawaiian Brain Health and outreach to populations of heavy burden is a priority in fulfilling the mission of enhancing the quality of life for all of Hawai‘i’s people affected by ADRD.

Caregiver support is also central to the State Strategic Plan, as an estimated 60,000 unpaid family caregivers in Hawai‘i are caring for a person with memory loss, and a significant increase in persons living with dementia from various cultures in Hawai‘i is anticipated. Different messages related to brain health, caregiving, and targeting the different levels of prevention that reflect cultural variations in views of health, disease diagnosis, and preferred help and treatments are needed. Representatives from groups working with Asian American and Pacific Islander communities will be invited to participate on the advisory committee and workgroups to provide guidance in messaging to those population groups. The Native Hawaiian Road Map also offers recommendations on providing dementia and brain health information to Native Hawaiians, especially in rural areas on O‘ahu, Hawai‘i, Maui, Kaua‘i, Moloka‘i, and Lāna‘i.

In 2023, EOA filled the Alzheimer’s Disease and Related Dementias Services Coordinator position in the Executive Office on Aging “to coordinate the provision of public and private Alzheimer’s disease and related dementia services” pursuant to HRS 349-3.2.

The ADRD Services Coordinator will collaborate with community organizations and coalition partners to implement the Hawai‘i 2035: State Strategic Plan on ADRD by using data to inform policies and practices, strengthen community-clinical linkages, increase the awareness and understanding of ADRD and brain health, and develop the workforce capacity for professionals, paraprofessionals, and caregivers.

EOA and the coalition partners appreciate and look forward to continuing to work with many stakeholders to build a strong infrastructure, reduce the risk of cognitive decline, promote healthy brain development, and support caregivers who are caring for individuals with dementia.

# INTRODUCTION

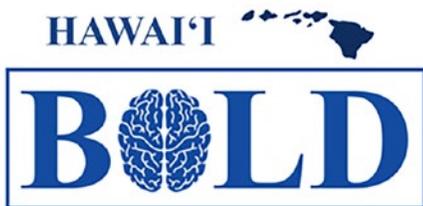
In 2007, the Alzheimer’s Association and the Centers for Disease Control and Prevention (CDC) published the Healthy Brain Initiative Road Map, A National Public Health Road Map to Maintaining



## HEALTHY BRAIN INITIATIVE

Cognitive Health, to advance cognitive health as a part of public health. Since then, the Road Map was updated in 2013, 2018, and most recently in 2023, State and Local Road Map for Public Health, 2023–2027. These road maps provide action agendas for the public health community to build a foundation, strengthen capacity, and develop partnerships to work on policies, systems, and environments to reduce the risk of cognitive decline, Alzheimer’s disease, and other dementias.<sup>1</sup> The goal is to bring a life course, public health approach to brain health, because everyone deserves a life with the healthiest brain possible.<sup>2</sup> On December 31, 2018, Congress passed P.L. 115-406, the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act.<sup>3</sup> The activities discussed in this Act were designed to create a uniform national public health infrastructure with a focus on issues such as 1) increasing early detection and diagnosis, 2) risk reduction, 3) preventing avoidable hospitalizations, and 4) supporting dementia caregiving.

Meanwhile in Hawai‘i, a passionate group of community stakeholders convened in 2011 to discuss efforts that would greatly improve the way individuals with Alzheimer’s disease and related dementias (ADRD) and their families live in their communities and are served by institutions. These efforts led to the publishing of the Hawai‘i 2025: State Plan on Alzheimer’s Disease and Related Dementias, in 2013. This inaugural plan was the culmination



of recommendations from seven workgroups of the Hawai‘i ADRD Task Force, caregiver and key informant surveys, and interviews with Hawai‘i experts and leaders, as well as recommendations from the 2012 National Plan to Address Alzheimer’s Disease.

In October 2020, the Hawai‘i State Executive Office on Aging (EOA) received a 3-year planning grant from the Centers for Disease Control and Prevention (CDC) as part of its Building Our Largest Dementia Infrastructure (BOLD) Public Health Programs to Address Alzheimer’s Disease and Related Dementias. The planning grant enabled EOA to update the Hawai‘i 2025: State Plan on Alzheimer’s Disease and Related Dementias in accordance with HRS 349-6.5, and align it with the CDC’s Healthy Brain Initiative 2018-2023 Roadmap.

This updated Hawai‘i 2025: State Strategic Plan on Alzheimer’s Disease and Related Dementias is aligned with both the BOLD Act<sup>3</sup> and the Healthy Brain Initiative Road Map.<sup>2</sup> It proposes strategies and action items in four public health domains: 1) Data; 2) Program and Policy Change; 3) Public Awareness and Education; and 4) Workforce Development. EOA will use the goals, strategies, and action steps developed in this plan to promote implementation of the CDC’s Healthy Brain Initiative Road Map to serve all people in the state, especially disproportionately affected populations with heavy chronic disease burden using culturally relevant pathways that recognize and value diversity and differences in Hawai‘i’s multicultural communities. EOA will also work with community partners to focus on Native Hawaiians, utilizing recommendations from the Native Hawaiian Road Map — Navigating Impacts of Nā Ma‘i Poina: Alzheimer’s Disease and Related Dementias Among Native Hawaiians.<sup>4</sup>

A diverse group of community stakeholders generously volunteered their time to identify problems as well as seek solutions to the public health challenges presented by ADRD in our islands. The resulting strategic plan is a “living document” that will continue to evolve through further research, outreach, and engagement

with existing and new stakeholders. Framed as a public health concern, the building of a robust dementia care infrastructure is considered to be a community responsibility involving government agencies, health-care systems, community-based organizations, allied healthcare professions, educational institutions, families, caregivers, advocates, the private sector, and others.

The goals, recommendations, and action steps contained in this plan will be accomplished through the efforts of people and organizations working together in a coalition to achieve successful outcomes in areas such as reducing the risk of ADRD in Hawai‘i’s general population and the Native Hawaiian population. Their efforts will promote early detection and diagnosis, improve safety and quality of care for people living with cognitive impairment, and expand public awareness and education that takes into consideration issues of health equity, cultural diversity, and inclusion. They will also attend to caregivers’ health and well-being, developing pathways to a dementia-capable workforce at all levels of the health-care sector, and encourage constructive changes in policies, systems, and environments, especially for high-risk populations such as Asian Americans, Native Hawaiians, and Pacific Islanders (AANHPI).

## BACKGROUND ON ADRD

**Dementia** is a general term for a group of symptoms such as memory loss, difficulties with language, problem-solving, and other cognitive functions caused by abnormal changes in the brain, damage to brain cells, and/or various brain diseases. Types of dementias include but are not limited to Alzheimer’s disease, Frontotemporal dementia, Lewy body dementia, Vascular dementia, Hippocampal sclerosis, Parkinson’s disease, mixed dementias, Huntington’s disease dementia, Creutzfeldt-Jakob disease, dementia caused by traumatic brain injury, alcohol-related brain impairment, and Wernicke-Korsakoff Syndrome. The World Health Organization estimates that dementia affects more than 55 million people worldwide,<sup>5</sup> however, about 75% of dementia cases go undiagnosed.<sup>6</sup> In Hawai‘i, 1 in 9 adults 45 years or older reported experiencing subjective cognitive decline because they noticed worsening memory problems over the past year in 2021.<sup>7</sup> Not everyone who experiences subjective cognitive decline will develop dementia, but this can be one of the earliest indicators to be screened for potential signs of dementia. Dementia is progressive, which means that it gets worse over time and it is typically diagnosed later in life. However, there are some younger or

### 10 WAYS TO LOVE YOUR BRAIN

**START NOW.** It's never too late or too early to incorporate healthy habits.



**BREAK A SWEAT** Engage in regular cardiovascular exercise that elevates heart rate and increases blood flow. Studies have found that physical activity reduces risk of cognitive decline.



**HIT THE BOOKS** Formal education will help reduce risk of cognitive decline and dementia. Take a class at a local college, community center or online.



**BUTT OUT** Smoking increases risk of cognitive decline. Quitting smoking can reduce risk to levels comparable to those who have not smoked.



**FOLLOW YOUR HEART** Risk factors for cardiovascular disease and stroke – obesity, high blood pressure and diabetes – negatively impact your cognitive health.



**HEADS UP!** Brain injury can raise risk of cognitive decline and dementia. Wear a seat belt and use a helmet when playing contact sports or riding a bike.



**FUEL UP RIGHT** Eat a balanced diet that is higher in vegetables and fruit to help reduce the risk of cognitive decline.



**CATCH SOME ZZZ'S** Not getting enough sleep may result in problems with memory and thinking.



**TAKE CARE OF YOUR MENTAL HEALTH** Some studies link depression with cognitive decline, so seek treatment if you have depression, anxiety or stress.



**BUDDY UP** Staying socially engaged may support brain health. Find ways to be part of your local community or share activities with friends and family.



**STUMP YOURSELF** Challenge your mind. Build a piece of furniture. Play games of strategy, like bridge.

Growing evidence indicates that people can reduce their risk of cognitive decline by adopting key lifestyle habits. When possible, combine these habits to achieve maximum benefit for the brain and body.

**Visit [alz.org/10ways](http://alz.org/10ways) to learn more.**

**alzheimer's association**  
THE BRAINS BEHIND SAVING YOURS.

early-onset cases, which affect individuals before the age of 65, primarily in their 30s, 40s, or 50s. To date there is no cure for this disease. However, studies have shown that proactive management of dementia can improve quality of life for persons living with dementia and their caregivers.<sup>8</sup>

**Alzheimer's disease** is the most common type of dementia. It is a type of brain disease that affects more than 6.7 million people in the United States, and women comprise almost two thirds of this group.<sup>9</sup> In the state of Hawai'i, which has a total population of over 1.4 million people,<sup>10</sup> it is estimated that 29,000 older adults (i.e., 65 years and older) live with Alzheimer's disease and are cared for by 60,000 family caregivers as of 2020. These caregivers provide 91 million hours of unpaid care valued at more than \$1.9 billion<sup>11</sup> and is a critical component of the long-term care support network for Hawai'i's multi-cultural older adults. By 2025, the number of people living with Alzheimer's disease in Hawai'i is expected to rise to 35,000, a more than 20% increase from 2020.<sup>8</sup> Alzheimer's disease is the sixth leading cause of death in Hawai'i.<sup>12</sup>

Researchers continue to investigate treatments, preventative measures, and protective factors for ADRD. Some of the topics of current research studies include removing amyloid plaques and tau tangles, increasing the soluble amyloid-beta, monitoring glucose levels, and improving the synaptic plasticity in the brain.

As of July 2023, there are currently two FDA-approved treatments, lecanemab (Leqembi™) and aducanumab (Aduhelm™), that target beta-amyloid plaques in the brains of those with early-stage Alzheimer's disease. Both are currently administered intravenously (IV) periodically. These are not cures and will not restore lost memories or cognitive functions. However, they focus on slowing the progression of the disease to prolong one's ability to function independently. There is a risk of side effects, and individuals who choose these (and any) drug therapies should be informed and understand the risks associated with treatment. It is very important for individuals to talk with their healthcare provider to discuss their options, find out what is right for them, determine eligibility, and seek potential availability of the treatments if appropriate. These drugs can be very expensive, and advocates continue to urge health insurance plans to cover them. Other drugs are currently in development. Researchers continue to conduct clinical trials to search for effective, safe treatments, and hopefully one day, a cure.

## 10 Warning Signs of Alzheimer's



- 1 Memory loss that disrupts daily life:** forgetting events, repeating yourself or frequently relying on more aids to help you remember (like sticky notes or reminders).
- 2 Challenges in planning or solving problems:** having trouble paying bills or cooking recipes you have used for years.
- 3 Difficulty completing familiar tasks at home, at work, or at leisure:** having problems with cooking, driving places, using a cell phone, or shopping.
- 4 Confusion with time or place:** having trouble understanding an event that is happening later, or losing track of dates.
- 5 Trouble understanding visual images and spatial relations:** having more difficulty with balance or judging distance, tripping over things at home, or spilling or dropping things more often.
- 6 New problems with words in speaking or writing:** having trouble following or joining a conversation or struggling to find a word you are looking for (saying "that thing on your wrist that tells time" instead of "watch").
- 7 Misplacing things and losing the ability to retrace steps:** placing car keys in the washer or dryer or not being able to retrace steps to find something.
- 8 Decreased or poor judgment:** being a victim of a scam, not managing money well, paying less attention to hygiene, or having trouble taking care of a pet.
- 9 Withdrawal from work or social activities:** not wanting to go to church or other activities as you usually do, not being able to follow football games or keep up with what's happening.
- 10 Changes in mood and personality:** getting easily upset in common situations or being fearful or suspicious.

**Risk Factors.** There are multiple risk factors for dementia, but the strongest risk factor is age. Hawai'i has the highest life expectancy in the U.S. with a record of 80.7 years, and the state's median age is 40.2 years.<sup>12</sup> There have been recent findings about modifiable risk reduction factors that focus on optimizing brain health and decreasing the likelihood of dementia. Individuals with chronic conditions, heart disease, hypertension, stroke, diabetes, traumatic brain injury, excessive alcohol consumption, smoking, poor sleep quality, hearing loss, and adverse childhood experiences are at a higher risk for cognitive decline and dementia.<sup>13,14</sup> Older adults with ADRD are more likely to have multiple chronic conditions. Over 95% of people with ADRD have one or more other chronic conditions. A person with ADRD is more than 3.8 times as likely to have six or more other chronic conditions as someone without ADRD.<sup>15</sup> ADRD also complicates the management of these chronic conditions.

Down syndrome may also be a risk factor for Alzheimer's disease. About 50 percent of individuals with Down syndrome may develop Alzheimer's disease as they age.<sup>16</sup> Dementia is also more likely to go undetected in individuals with intellectual and developmental disabilities (I/DD), which often leads to later diagnosis and intervention.<sup>2</sup> According to the CDC, scientists believe that chromosome 21 plays a key role in the relationship between Down syndrome and Alzheimer's disease.<sup>17</sup> Individuals with Down syndrome have an extra chromosome 21 which is the gene that produces the amyloid protein associated with Alzheimer's disease. Individuals with Down syndrome are also likely to have severe issues related to their heart, which places them at an increased risk for early onset dementia. However, not all individuals with Down syndrome develop Alzheimer's disease as they age. Specialized assessment tools and diagnostic resources are needed to measure neurocognitive decline in individuals with I/DD because mainstream assessments may be inadequate to detect dementia in neuroatypical adults.<sup>18</sup> Differential diagnosis is vital to discern whether symptoms are attributable to dementia or other conditions such as Regression. More research and clinical trials are needed to understand the relationship between intellectual and developmental disabilities, such as Down syndrome, with Alzheimer's disease and related dementias so that pharmacological and non-pharmacological treatments can be developed.

Of all the ethnicities in Hawai'i, Native Hawaiians currently have the highest possibility for developing dementia related to the prevalence of risk factors, especially chronic conditions, significant health disparities, and social determinants of health. This can be attributed to cultural intergenerational trauma and "a complex reaction to the obliteration of 'Ōiwi cultural and medicinal practices, land occupation, spiritual devastation, introduced infections, and decline in social status,"<sup>19</sup> as referenced in the Native Hawaiian Road Map 2023.<sup>4</sup> Although this burden continues to weigh heavily on Kānaka Maoli for generations, this indigenous population has "tremendous resilience in

<b>Next Steps After Diagnosis<sup>42</sup></b>	
●	<b>Learn more about your diagnosis</b> -Talk to your doctor. -Call the Alzheimer's Association at (800) 272-3900.
●	<b>Get regular medical care</b> -Make regular appointments with Primary care physician and specialists (neurologist, neuropsychiatrist, geriatrician, geriatric psychiatrist).
●	<b>Plan for your future</b> -Prepare an Advance Healthcare Directive, Power of Attorney, and POLST form.
●	<b>Find services and supports</b> -Call the Hawai'i Aging and Disability Resource Center at (808) 643-2372. -Tell a trusted family or friend so they can support you. -Join a support group.
●	<b>Make everyday tasks easier</b> -Take notes and use a calendar. -Automate bill payments. -Ask family or friend for help with routine tasks like cooking, shopping, transportation. Simplify your life.
●	<b>Be safe at home</b> -Get home-safety tips. <a href="http://www.nia.nih.gov/health/home-safety-checklistalzheimer-disease">www.nia.nih.gov/health/home-safety-checklistalzheimer-disease</a> -Consider wearing a medical ID bracelet in case you get lost or need help.
●	<b>Stay healthy</b> -Stay social and exercise regularly! Eat a well balanced diet.



# CHOOSE Brain-Healthy Habits

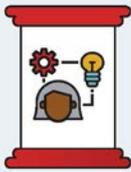
Simple steps can make a difference

## Six Pillars of Brain Health



### Be Social

Keep in touch with friends & family, don't let yourself get isolated.



### Engage Your Brain

Find ways to stimulate your thinking, explore new interests and hobbies.



### Manage Stress

Practice relaxation, take time for yourself.



### Ongoing Exercise

Move throughout the day, target 2½ hours a week of moderate physical activity.



### Restorative Sleep

Get 7–8 hours of restful sleep every day.



### Eat Right

Choose a nutritious, heart-healthy diet of fish, veggies, and fruits.

## 4 Steps to Get Started:

- ✓ Set a goal, identify a specific action you want to take.
- ✓ Find something fun; choose what you enjoy.
- ✓ Re-purpose some of your free time to make room for new healthy habits.
- ✓ Involve friends or family with common goals.

Learn more about the Six Pillars: [GlobalCouncilonBrainHealth.org](https://www.globalcouncilonbrainhealth.org)

*How to Sustain Brain Healthy Behaviors: Applying Lessons of Public Health and Science to Drive Change*  
Contact: GCBH@aarp.org | For more information on brain health see [StayingSharp.org](https://www.stayingsharp.org) | DOI: <https://doi.org/10.26419/pia.00106.008>



Global Council on  
**Brain Health**  
A COLLABORATIVE FROM **AARP**

the face of foreign-imposed political, economic, and educational structures. It is through these multiple lenses that we understand the challenges, disparities, and evolution of Kānaka Maoli health” as reported in Ka Huaka’i: Native Hawaiian Educational Assessment 2021.<sup>19</sup> About 21% of the total population of Hawai’i identify as Native Hawaiian alone or in any combination, a total of 309,807 people. Of that number, about 12% are age 65 and over.<sup>27</sup>

**Healthy behaviors** can optimize brain health and generally reduce the risk of cognitive decline or dementia. Behaviors such as restorative sleep, eating a balanced heart healthy diet, regular exercise, staying socially engaged, challenging your mind, managing stress, quitting smoking, and taking care of your mental health are simple steps that can make a big difference.<sup>13</sup> Those who use hearing aids or cochlear implants for hearing loss may also lessen their risk for developing dementia that is associated with hearing loss.<sup>14</sup> It is especially important for caregivers to take care of their overall health and well-being as they care for others.

**Challenges.** Due to a combination of demographic, social, and economic factors, the availability of informal (unpaid) and formal (paid) care will not necessarily increase accordingly with the growing older adult population. The direct care workforce is declining, which will result in a potential critical shortage of direct care workers for Hawai’i’s older adults seeking assistance with a range of care needs and supported living arrangements. Older adults with dementia, especially in the more advanced stages, have particularly intensive care needs due to their growing reliance on others for assistance with their activities of daily living and instrumental activities of daily living. In the late stages, persons with ADRD experience more functional and health declines, are often non-communicative, and their end-of-life periods tend to last longer than those without ADRD.<sup>20</sup> These impact the caregivers’ experiences and need for resources as they provide more involved care for persons living with dementia. Caregivers who are employed and have a loved one with moderate/high dementia demand

experience significantly greater challenges with caregiver burden, stress levels, job/caregiving conflicts, negative impacts on mood, and their ability to meet their own medical care needs than their counterparts.<sup>21</sup> These challenges are related to the increased need for assistance with decision-making, managing behaviors, and mental health issues on top of assistance with activities of daily living as previously stated. In 2021, about 31% of caregivers in Hawai‘i were caring for persons living with dementia.<sup>22</sup> Nearly half of them report having at least one chronic condition and 16.5% report experiencing depression.<sup>11</sup>

Providing care to a family member with dementia can be overwhelming and beyond the capabilities of some family caregivers for a variety of reasons. Even with adequate training, caregiver support, and respite opportunities, there may be instances when a family member can no longer safely provide the level of care needed. In these situations, looking into alternative supports may be the best option, whether it be bringing in direct care professionals to provide services in home or moving the person living with dementia to a supportive living environment outside the home. This



can be a difficult decision and process which may require the professional services of individuals or organizations trained to help families with such a transition. There are a variety of long-term services, supports, and care settings in Hawai‘i, and the “right” one for a person living with dementia depends on a number of different factors, including the level of care needed, cost, location, size, amenities and programs provided, personal preferences, and so forth.

Although persons living with dementia are more likely to receive support from multiple unpaid caregivers, there are a number of individuals who live alone with dementia.<sup>8</sup> Social isolation is common among those living with ADRD. One of many reasons for this is that the challenges that come with ADRD often cause people to withdraw from social activities. It is more common for individuals in the early stages of ADRD to live alone with the right supports and services in place. However, as the disease progresses, the ability to independently manage activities of daily living decreases and the importance of having an informal and/or formal support system increases.

One major demographic change in American society that is having, and will continue to have, a profound impact on family caregiving is the growing number of people who are entering older adulthood without children. According to a U.S. Census Bureau analysis of 2018 population data, 16.5% of adults 55 and older were childless (defined as having no biological children). This is a reflection of declines in marriage and fertility in the general population.<sup>23</sup>

Childlessness, according to the U.S. Census report, is more common among the younger cohort of older adults, which suggests that growing numbers of older adults in the future will be childless. As adult children comprise a significant number of family caregivers, this demographic shift highlights the necessity and urgency of finding alternatives to family caregivers for those elders who will need assistance with their activities of daily living and instrumental activities of daily living due to physical and cognitive declines.

A dwindling support network is increasingly seen in LGBTQIA+ older individuals who are 34% more likely to live alone than heterosexual counterparts.<sup>24</sup> LGBTQIA+ older adults are less likely to have children, less likely to be married, more likely to have chosen family members as caregivers, and more likely to be cared for by an individual who is the same age as them.<sup>2</sup> One study reported that about 25% of LGBTQIA+ adults (age 50-92) reported experiencing subjective cognitive decline, and this was significantly associated with depressive symptoms, as well as identifying as an ethnic minority.<sup>25</sup> Gender identity can impact one's aging experience in today's society due to stigma and discrimination.

With critical workforce shortages in the healthcare field, especially in the direct care workforce, which is predicted to worsen without interventions, older adults with dementia symptoms who are aging alone (or aging with insufficient family caregiver support) are of particular concern. Programs and policies to find solutions to this emerging gap in care are needed and require cross-sector planning and collaboration.

Because a person living with dementia can live for years, in some cases up to a decade or longer, the question of how to pay for the long-term care costs associated with a progressive brain disease like Alzheimer's is a critical one for people living with dementia and their family caregivers. Moreover, persons living with dementia may have other health problems (i.e., co-morbidities) that need attention, compounding the cost of care. How all of these associated costs get paid for depends on the financial situation of the person living with dementia and the specific services required for that person's care, as well as the availability and willingness of people (e.g., family members) to provide unpaid care when possible. One major concern that many older adults face is the possibility of outliving their resources.

The financing of long-term care could involve a variety of sources: personal funds, government assistance and programs, and private financing. Because long-term care costs — especially if a person has extensive care needs — can be exorbitant, it is advisable to begin financial planning with a trusted, qualified professional years and even decades before such care is needed. Once care is needed that exceeds what informal, unpaid caregivers are willing and able to provide, a qualified professional such as a benefits specialist should be able to help identify existing services and supports in the community. Envisioning and enacting effective solutions to the long-term care needs of an aging population must be a top priority for key stakeholders from different sectors of society working in collaboration with each other.

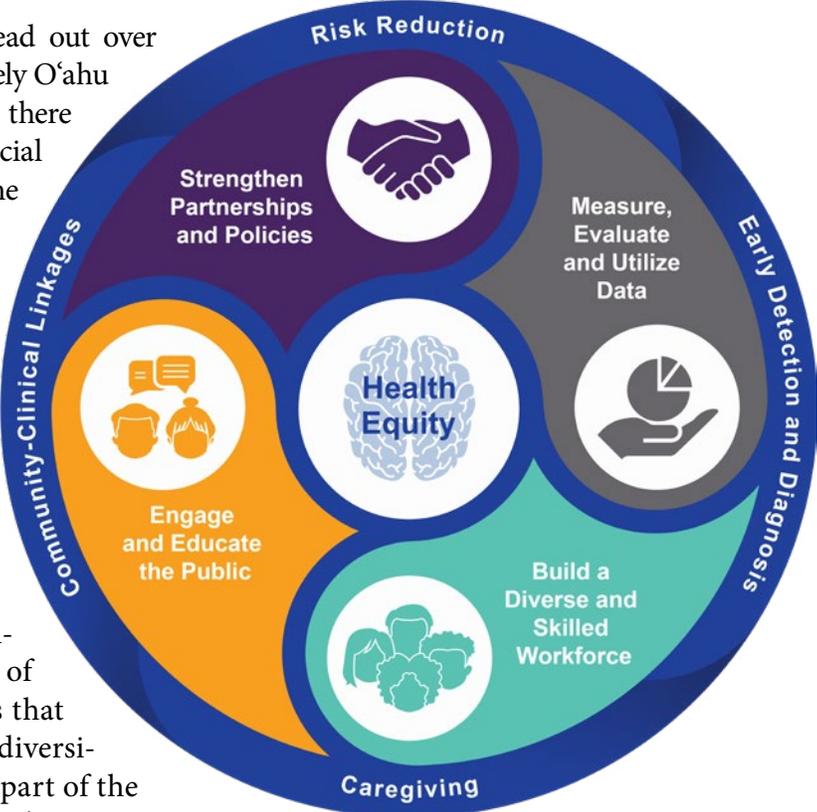
Living with dementia also increases the risk of mistreatment, elder abuse and neglect, and self-neglect.<sup>26</sup> Persons living with dementia may have decreased mental and physical capacity due to ADRD, brain changes that may lead to mood and behavior changes, difficulty identifying and reporting abuse or neglect, and apprehension about the repercussions of reporting, which causes them to be more vulnerable or susceptible to mistreatment.

Other contributing factors are increased caregiver burden and ageist stereotypes. With these challenges in mind, it is critically important to remediate, reduce, and prevent the mistreatment of persons living with dementia.



Recognizing that Hawai‘i’s population is spread out over seven islands, with one of those islands — namely O‘ahu — hosting the largest number of people by far, there is also the concern over access to healthcare, social services, and supports for residents living in the rural areas of neighboring islands: Lāna‘i, Molo-ka‘i, Maui, Kaua‘i, and Hawai‘i Island. Some of the challenges that rural communities face are limited resources, staffing shortages, lack of providers, insufficient agencies, facility closures, and travel difficulties. However, each island is unique and deserves support tailored to their specific island community.

Systematic discrimination and inequities in social determinants of health contribute to the risk of developing dementia and barriers in accessing much needed care. In light of health inequities, disparities, and challenges that affect our communities, it is important that diversity, equity, and inclusion remain an essential part of the planning and implementation of this Hawai‘i 2035: State Strategic Plan on Alzheimer’s Disease and Related Dementias. Everyone deserves a life with the healthiest brain possible.<sup>2</sup>



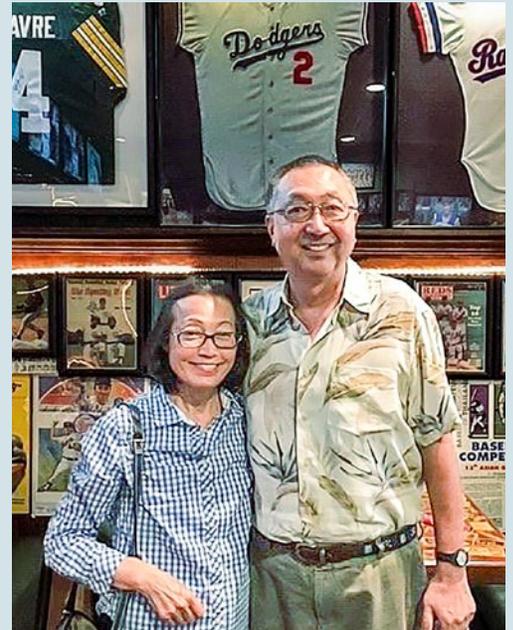
Conceptual Framework for the Healthy Brain Initiative Road Map 2023-2027<sup>2</sup>

## Inspiring Joy with Creativity & Reminiscence

Although people living with dementia typically experience cognitive deficits that can affect their quality of life in negative ways, there are creative activities that can still inspire joy and contentment by tapping into emotions and memories retained from decades earlier.

Dementia symptoms often manifest as problems with short-term memory early on in the course of the disease, but long-term memories may still be present and can be creatively integrated as a form of non-drug therapy. For example, the late Michael Ego, who used to be a university professor in Connecticut, spearheaded an activity that tapped into baseball fans’ memories of a sport that they enjoyed before they developed dementia symptoms. Ego found that even with dementia, these fans were still able to positively relate to the game later in life. They retained knowledge of the game, and more importantly, the positive emotions that they associated with baseball. Ego would go with the participants of a baseball reminiscence program to a live game and notice how the participants would laugh and have a good time alongside fellow fans who did not have dementia. That spirited enthusiasm so common at baseball games was shared by all. After Ego passed away in 2019, his sister, Kimi Ego, has been spreading her late brother’s passion for baseball reminiscence. During the pandemic, baseball fan attendance moved to Zoom when in-person attendance was not advisable for safety reasons. But even on Zoom, persons living with dementia could sing along to the national anthem, “God Bless America,” and “Take Me Out to the Ballgame,” just like at live games, and talk about their favorite baseball memories from the past, memories that might extend back to child-

hood relationships and experiences. At in-person gatherings, elders with dementia could watch televised games together — perhaps as part of a senior activity program — while eating hot dogs, drinking sodas, talking story about their baseball memories, and enjoying other baseball-related activities. They might even don baseball caps and jerseys, just to get into the spirit. A version of baseball reminiscence therapy might be tried in Hawai'i given the sport's extensive popularity in Hawai'i's past, including the local amateur leagues that started in the late 1800s and early 1900s when teams from different ethnic groups competed against each other. For generations thereafter, baseball has continued to be popular in Hawai'i at the amateur, collegiate, and professional levels (although Hawai'i has not had a professional team in recent times). Popular Japanese Major League Baseball players have attracted intense attention both locally and nationally. For more information about baseball reminiscence, see [www.SABRbaseballmemories.org](http://www.SABRbaseballmemories.org).



Other creative activities for elders with dementia could involve music. Research has demonstrated that even elders with more advanced dementia can often be positively stimulated by listening to music that they enjoyed earlier in their life when their brains were still functioning normally. There are former musicians who have been able to play musical instruments even though their dementia symptoms are progressing and they have trouble communicating verbally. The part of the brain that controls musical ability may still be working. A non-profit organization called Music Mends Minds “creates musical support groups for individuals with Alzheimer’s, dementia, Parkinson’s, traumatic brain injury, PTSD, and other neurological disorders,” according to its mission statement. Music Mends Minds was founded by Carol Rosenstein after her husband, Irwin, developed Parkinson’s disease and dementia symptoms.

Carol enrolled Irwin in the UCLA Alzheimer’s and Dementia Patient Care program and noticed that when Irwin played the piano for others in or associated with the program, it had an empowering effect on his life. Over time, he became “more aware, responsive, confident, energetic, talkative, and hopeful,” according to the organization’s website. “Hope and life came back into their home after Irwin’s passion for music was reignited. Carol consulted with their neurologist, who explained that “music may help stimulate increases in dopamine secretion from the brain for more sustained levels of energy and happiness.” Based on her and Irwin’s experiences, Carol started Music Mends Minds in 2014 and launched a live band called The 5th Dementia. Many participants, caregivers, and doctors provided positive feedback. During the pandemic, Zoom music sessions were held. The Music Mends Minds story has inspired others nationally and internationally to start their own groups. Intergenerational support and caregiver participation are encouraged. The Music Mends Minds website can be visited at [www.musicmendsminds.org](http://www.musicmendsminds.org).



Creativity and memories can also be therapeutic for caregivers of persons living with dementia. Caregivers often benefit from creative activities as well, but they may not have a lot of time to care for themselves. Poet Frances Kakugawa, born in Kapoho on Hawai'i Island and currently living in California, has spent decades helping caregivers express their thoughts and emotions through the healing art of



poetry. All they need is a pen and some paper or a notebook. An award-winning author of 17 books, Kakugawa used poetry writing during her own time as a caregiver for her mother, putting words to paper in poetic form to express things that can sometimes be too difficult to say another way. She has found that in her poetry writing workshops for caregivers, poems can help participants release words and feelings from inside themselves that had been kept unrevealed for a while. Kakugawa has also written a popular series of children's books around the character of a poetry-writing Hawaiian mouse named Wordsworth. In one of the books — *Wordsworth Dances the Waltz* — Wordsworth describes living with a grandmother who is experiencing symptoms of dementia. Wordsworth also observes that adult family members begin acting strangely around the house seemingly because of his grandmother's cognitive changes. He realizes that even though his grandmother has memory problems, she is still grandma to him and he discovers ways of spending quality time with her that make

her happy, including dancing. Kakugawa's books on caregiving include *I Am Somebody: Bringing Dignity and Compassion to Alzheimer's Caregiving* (2014), *Breaking the Silence: A Caregiver's Voice* (2010), and *Mosaic Moon: Caregiving through Poetry* (2002). In July 2023, Kakugawa presented a special workshop sponsored by Catholic Charities of Hawai'i called "Giving Voice and Dignity to Dementia Caregivers and Their Loved Ones." Kakugawa spoke directly to caregivers about the importance of self-care, affording dignity and understanding to the person living with dementia, and the potential benefits of using writing as a way to embrace the caregiver experience.

These are some examples of how to engage persons living with dementia and their caregivers in ways that use creativity and reminiscence. There are other examples. Some activities may be more appealing and effective than others, depending on the person's interests, abilities, and capacities. Other activities that a person with dementia at different stages may enjoy may include visiting a museum; going on a group walk; working in a garden with others; helping to prepare a meal with family members or a specific item like cookies or a cake; playing cognitively appropriate board games; looking through old photographs; participating on video calls with old friends and family members; interacting with a friendly pet; getting a manicure; helping set the table or clean up; folding laundry; talking about old times; listening to live or recorded music; speaking in a foreign language learned in childhood; looking at an aquarium; creating arts and crafts; doing activities that require sorting and organizing — the list goes on. There is no one-size-fits-all approach to using creativity and reminiscence with persons living with dementia and their caregivers. Culturally tailored and intergenerational activities should also be considered. The key components of the activity should be 1) the person living with dementia seems to enjoy it; 2) the activity is safe; and 3) the activity includes social interaction and a sense of inclusion.



# HAWAII POPULATION OVERVIEW

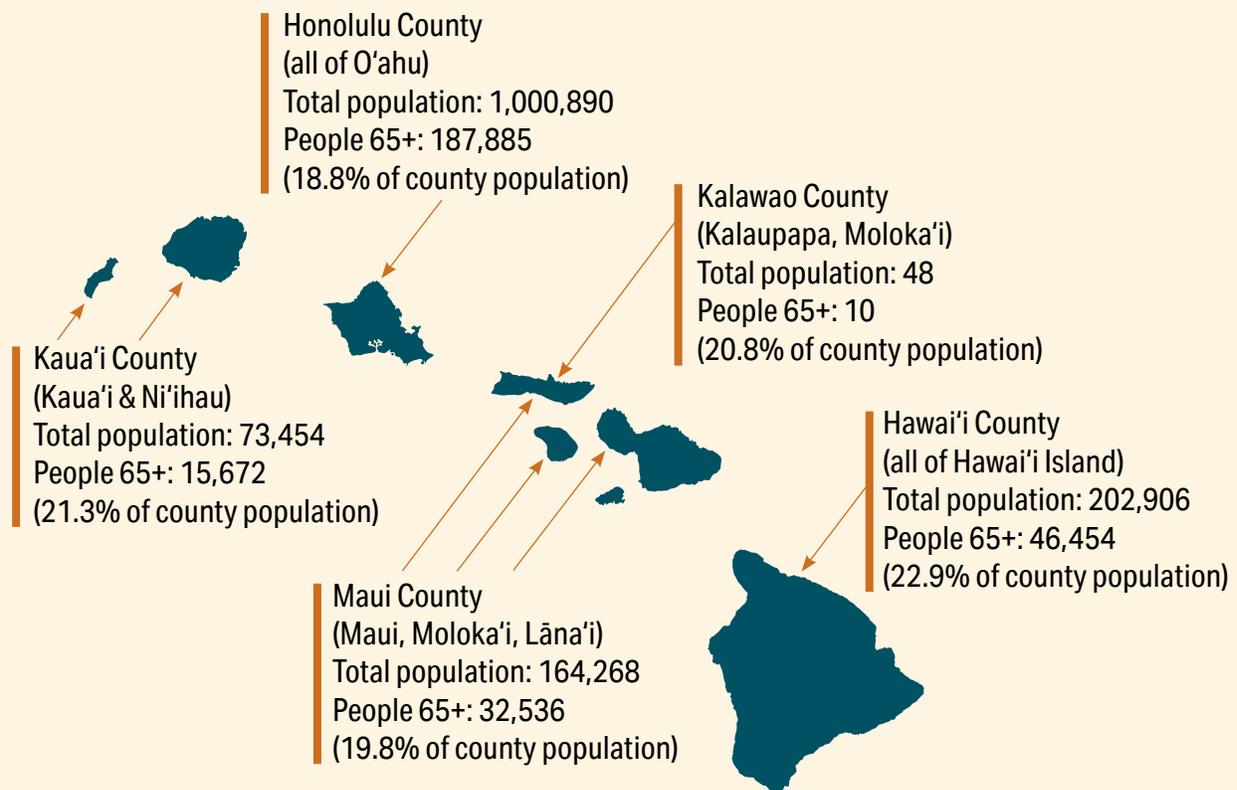
## The Population of Hawai'i: Total and 65+ Population

Table 1.

Area	Total	65+ Population	Percent 65+ Population	Distribution of statewide 65+ across counties
State of Hawai'i	1,441,553	282,567	19.6% (of total statewide pop.)	N/A
Honolulu County (all of O'ahu)	1,000,890	187,885	18.8% (of total O'ahu pop.)	66.5% (of statewide 65+ pop.)
Hawai'i County (all of the Hawai'i Island)	202,906	46,454	22.9% (of total Hawai'i Is. pop.)	16.4% (of statewide 65+ pop.)
Maui County (Maui, Lāna'i, Moloka'i)	164,268	32,536	19.8% (of total Maui County pop.)	11.5% (of statewide 65+ pop.)
Kaua'i County (Kaua'i, Ni'ihau)	73,454	15,672	21.3% (of total Kaua'i pop.)	5.6% (of statewide 65+ pop.)

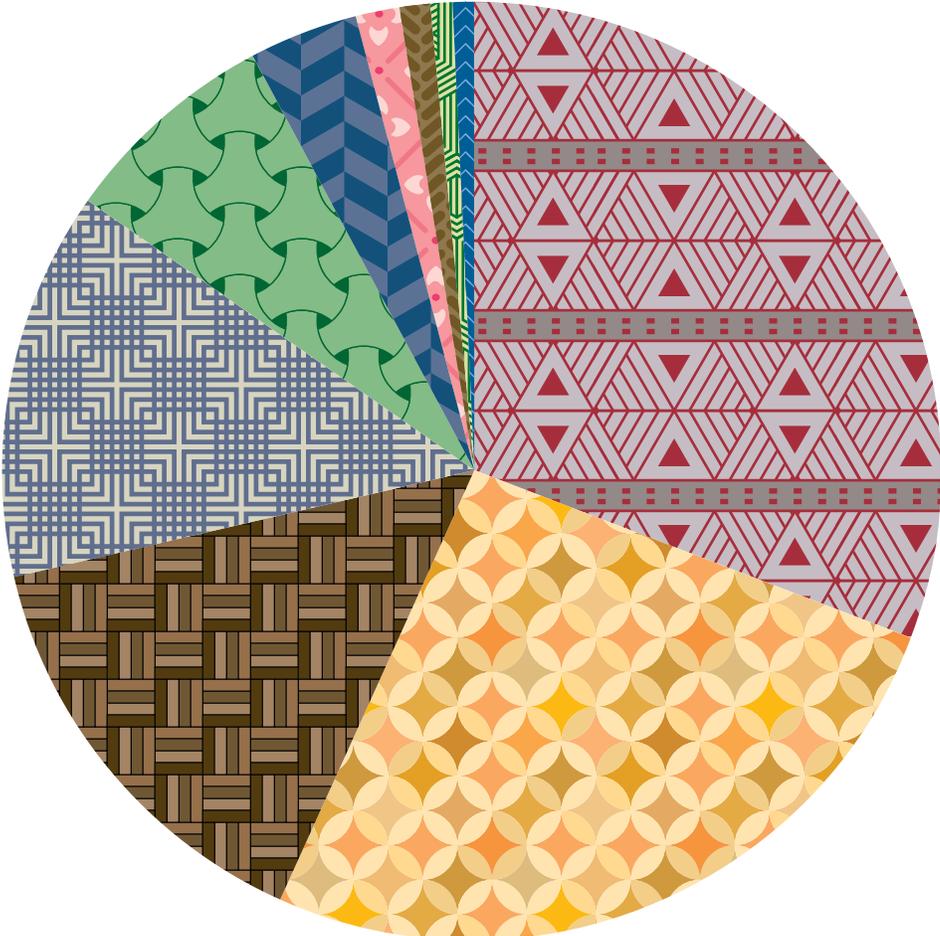
Source: United States Census Bureau, S0101: Age and Sex, Hawaii 2021: 1-Year Estimates Subject Tables<sup>27</sup>

Figure 1.  
Population of the State of Hawai'i by County



# The Ethnicities of the 65+ Population in Hawai'i

Figure 2.



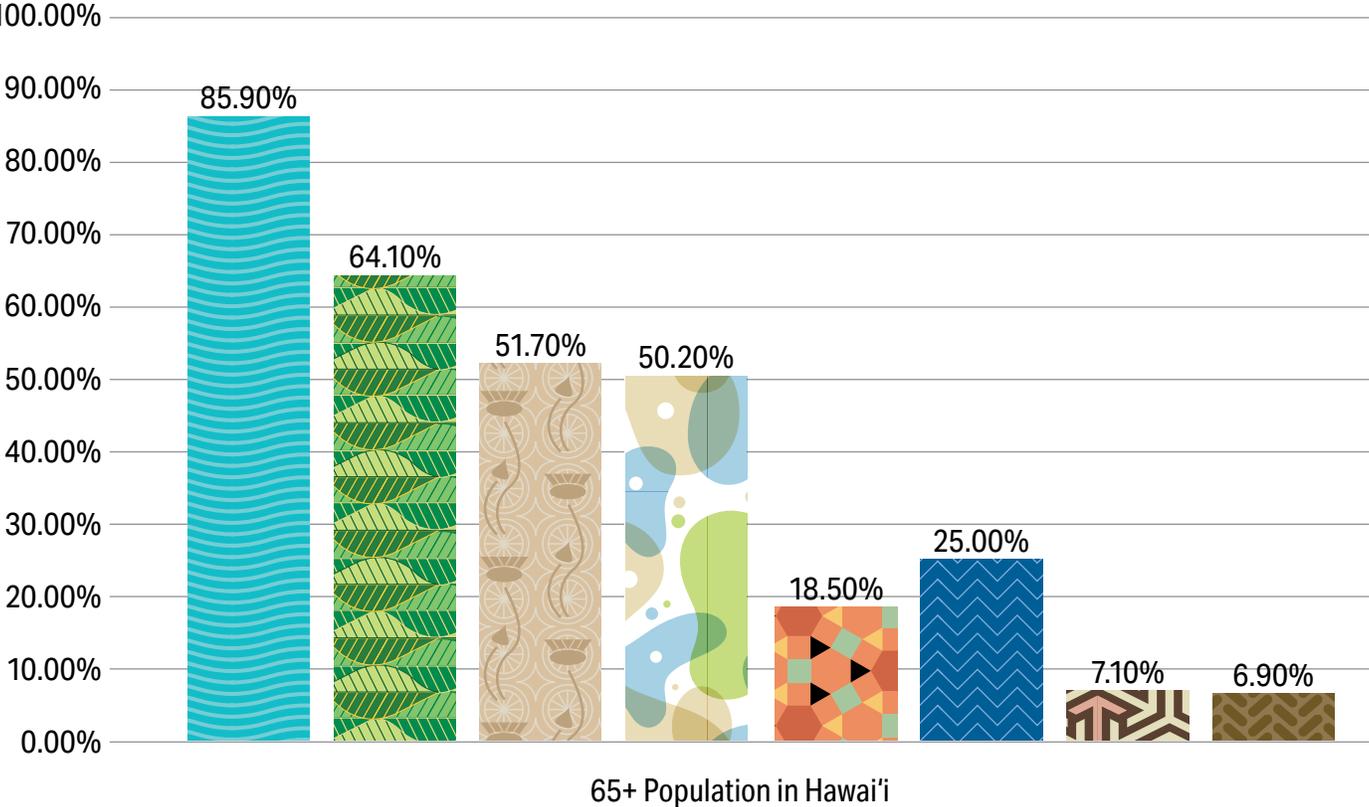
 White – 30.8%	 Other Asian – 3.7%
 Japanese – 25.9%	 American Indian / Alaskan Native – 1.5%
 Filipino – 14.6%	 Black – 1%
 Native Hawaiian – 13.3%	 Other – 0.8%
 Chinese – 7.6%	 Other Pacific Islander – 0.7%

This pie chart is displayed using patterns for individuals who are unable to differentiate certain colors.

Hawai'i State Department of Health, Hawai'i Health Data Warehouse, Behavioral Risk Factor Surveillance System. [DOH Race by Ethnicity, 2021]. Published [1 May 2023]. Accessed [13 Jun 2023]. [hhdw.org/report/query/result/brfss/DOHRaceNewCat/DOHRaceNewCatCrude11\\_.html](https://hhdw.org/report/query/result/brfss/DOHRaceNewCat/DOHRaceNewCatCrude11_.html) (Modify Query, Year 2021, Age Group 65+)

# The Prevalence of Chronic Conditions in the 65+ Population in Hawai'i

Figure 3.



- 1 or more chronic conditions
- 2 or more chronic conditions
- High blood pressure
- Cholesterol
- Diabetes
- Pre-diabetes
- Coronary heart disease
- Stroke

Hawai'i State Department of Health, Hawai'i Health Data Warehouse, Behavioral Risk Factor Surveillance System. [Chronic Conditions, 2021]. Published [1 May 2023]. Accessed [13 June 2023]: [hhdw.org/data-sources/behavioral-risk-factor-surveillance-system](http://hhdw.org/data-sources/behavioral-risk-factor-surveillance-system)

## ADRD Prevalence (%) by Age Group and Gender

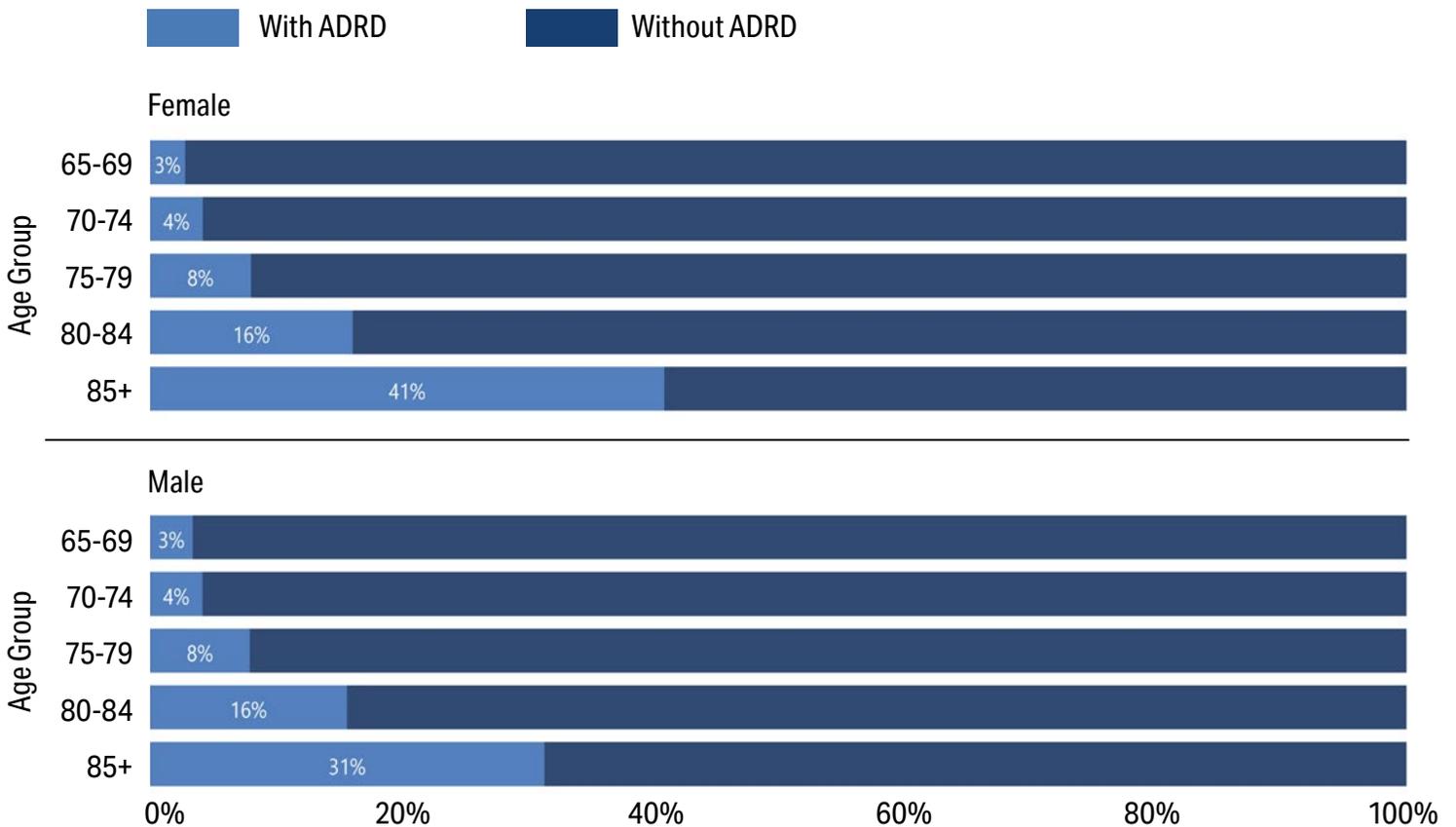
**Figure 4.**

### Prevalence

In an analysis of Hawai'i's Medicare population from 2010 to 2019, about 14% of beneficiaries were diagnosed with Alzheimer's Disease and Related Dementias (ADRD).

Prevalence of ADRD is generally higher among female beneficiaries compared to male beneficiaries, increasing as the population ages. Among the 85+ population, 41% of females and 31% of males have ADRD.

Figure 4 indicates that ADRD prevalence tended to increase with age and was higher in older female beneficiaries.



### Technical Notes and Comments (Figures 4 -7)

- Analysis conducted by UH TASI in Sept 2023
- Dataset includes Hawai'i Medicare beneficiaries (n = 136,008) and fee-for-service claims from years 2010-2019
- Diagnosis flags based on FFS claims, Medicare Advantage is not included
- Diagnosis identification based on 3-year look-back period; only beneficiaries with sufficient FFS coverage included
- Prevalence does not include undiagnosed or non-Medicare residents
- Cost includes payments made by Medicare, beneficiaries, and other primary payers (as recorded by CMS); adjusted to 2019 dollars
- Cost and utilization are based on all services received, not specifically ADRD-related services
- Medicare does not cover long-term care, so the costs of care related to ADRD are likely understated.

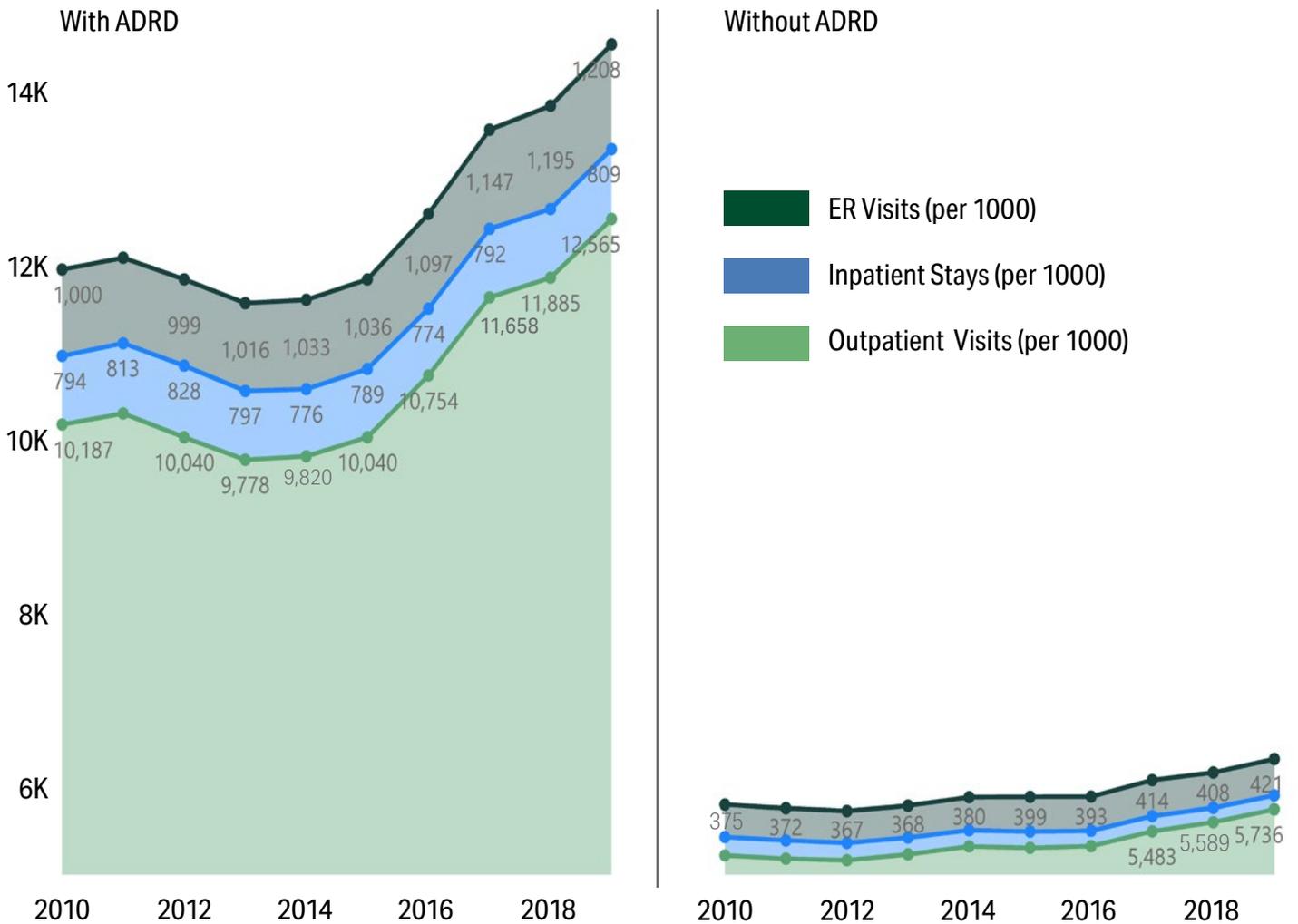
## Utilization by Diagnosis Status and Year

Figure 5.

### Utilization

Beneficiaries with ADRD experienced 4.3 times as many inpatient stays as beneficiaries without ADRD. They also experienced 2.7 times as many ER visits and 2.0 times the amount of outpatient (including home health) visits.

Figure 5 shows that Medicare service utilization is substantially higher among the ADRD population.



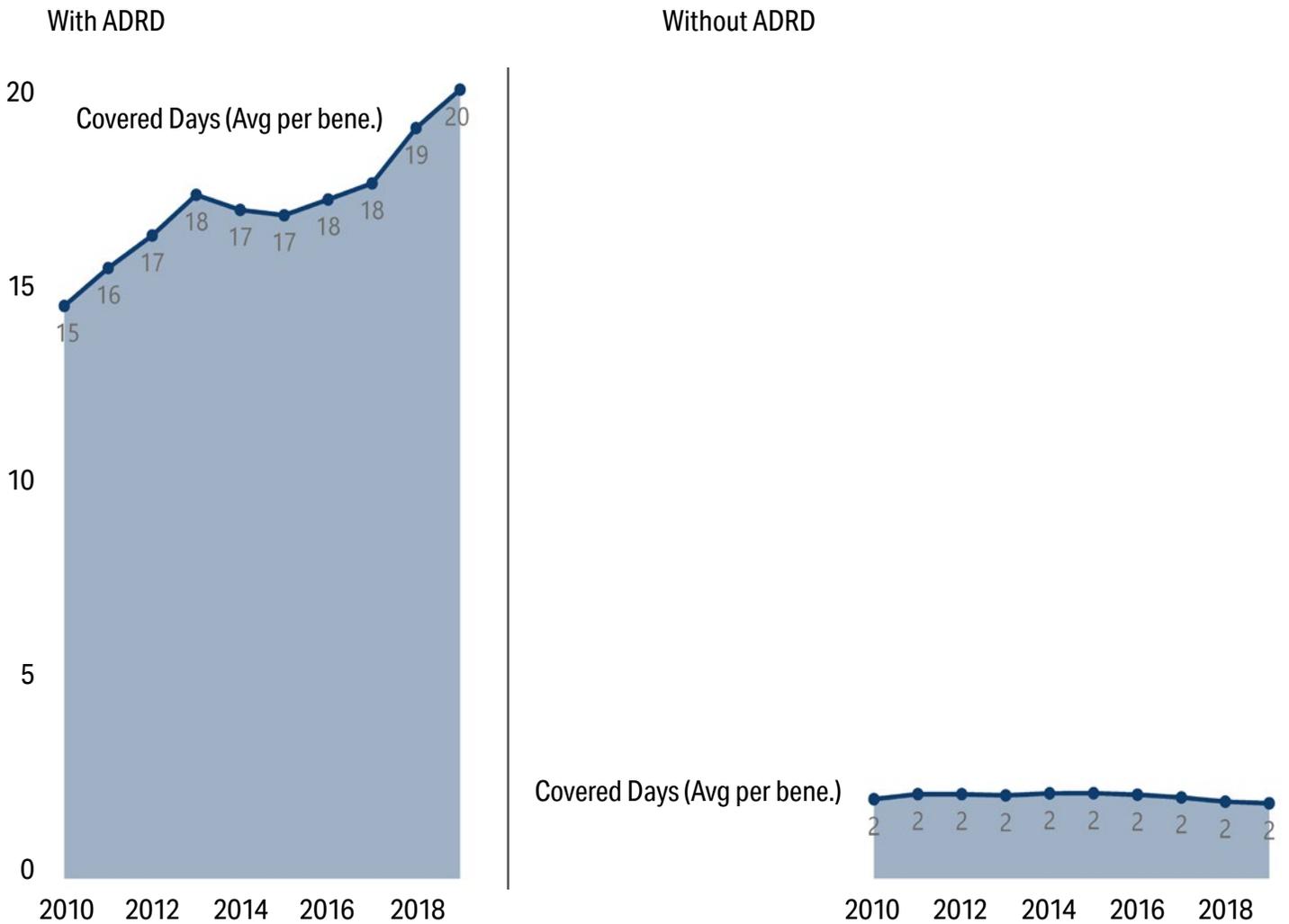
## Covered Days by Diagnosis Status and Year

Figure 6.

### Covered Days

In addition to accounting for more stays, beneficiaries with ADRD experienced longer lengths of stay (covered by Medicare), approximately 8.8 times longer than beneficiaries without ADRD.

Figure 6 shows that the average Medicare covered days were substantially longer among the ADRD population.



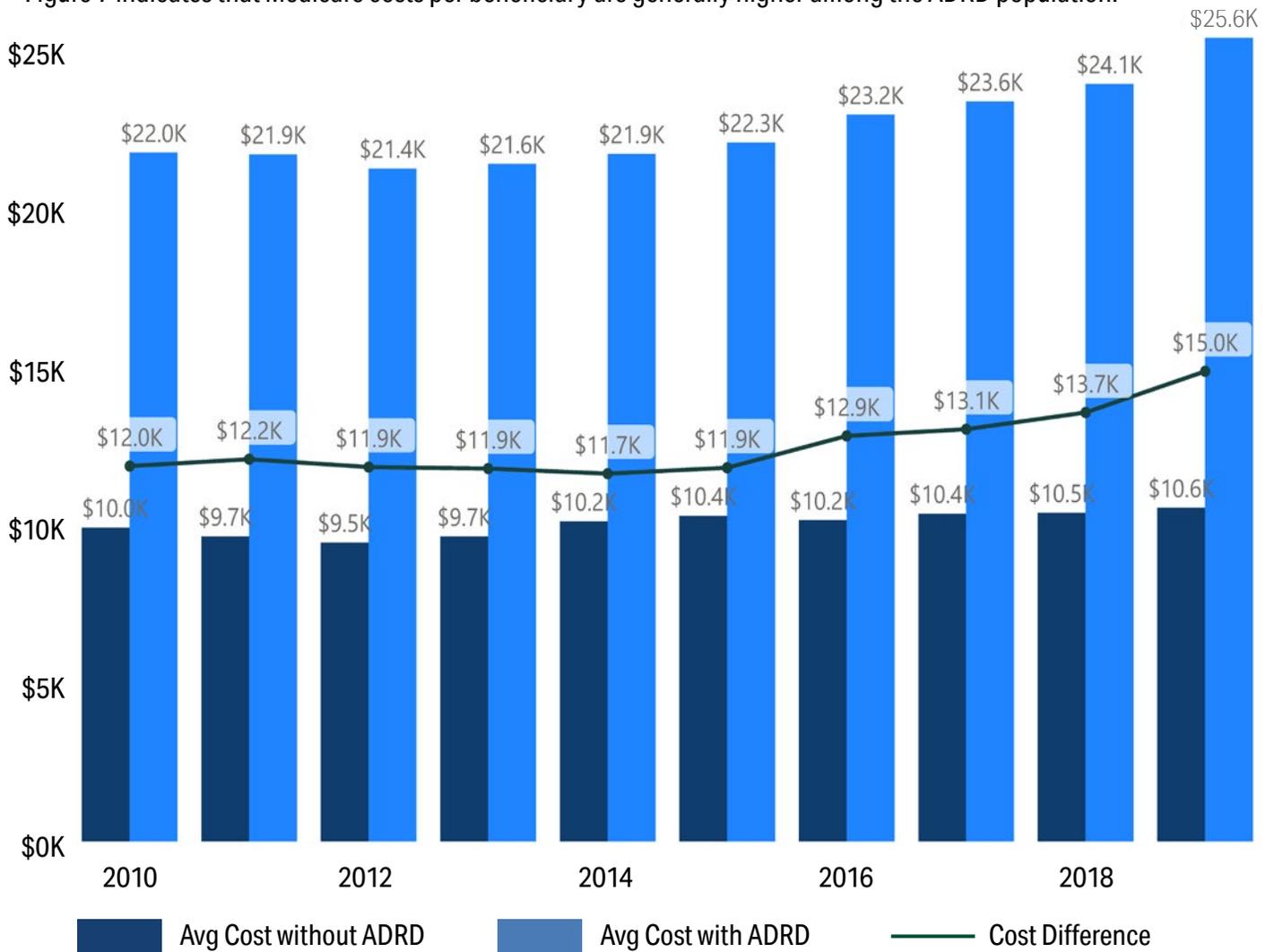
## Average Cost per Medicare Beneficiary by Diagnosis Status and Year

Figure 7.

### Cost

On average, Medicare costs were more than \$12,000 higher in the ADRD population compared to the non-ADRD population. The cost differential between these two groups also increased from 2010 to 2019.

Figure 7 indicates that Medicare costs per beneficiary are generally higher among the ADRD population.



## PURPOSE & APPROACH

*This next section, Purpose and Approach, provides updates on ADRD state plan implementation activities and revised strategies highlighting next steps toward creating statewide dementia capability.*

**H**awai‘i 2035: State Strategic Plan on Alzheimer’s Disease and Related Dementias builds upon and expands a previous update that was done since the original state plan was released in 2013. In 2020, as mandated by Chapter 349-6.5 Hawai‘i Revised Statutes to “prepare an update of the state plan on ADRD no less frequently than once per fiscal biennium,” the EOA contracted with the University of Hawai‘i’s Center on Aging (COA) to facilitate and prepare an update of the Hawai‘i 2025: State Plan on ADRD. Due to the COVID-19 pandemic, their work was restricted to virtual engagement of the ADRD taskforce. A survey was developed and distributed to persons with ADRD, caregivers, and professionals. A total of 141 respondents completed the survey. These survey results informed the state plan update in 2020, which became the foundation of this current plan.

As part of its continuing commitment to building and strengthening the state’s dementia care infrastructure, EOA partnered and collaborated with many government and community agencies including AARP, the four county ADRCs (Aging and Disability Resource Centers), Alzheimer’s Association - Hawai‘i, Hawai‘i Public Health Institute, Hawai‘i Pacific Gerontological Society, Papa Ola Lōkahi, Project Dana, Hawai‘i Family Caregiver Coalition, University of Hawai‘i Center on Aging, University of Hawai‘i Telecommunications and Social Informatics (TASI), Med-QUEST All Payers Claims Database, University of Hawai‘i Office of Public Health Studies, Hawai‘i Public Health Association, and the Department of Health Chronic Disease Prevention and Health Promotion Division. Partners and collaborators have supported the CDC BOLD Hawai‘i mission in a variety of ways, including participation in community outreach or in workgroup activities, including:



Partners and collaborators have supported the CDC BOLD Hawai‘i mission in a variety of ways, including participation in community outreach or in workgroup activities, including:

1. Data workgroup to review findings from three data sources (BRFSS, All Payers Claims Database and EOA’s ADRCs in-home assessment data) and discuss its implications for programs and policies.
2. Program and Policy Change workgroup to assess and ensure inclusion and expanded use of effective interventions by service providers to provide additional support to older adults and their caregivers.
3. Public Awareness and Education workgroup to discuss approaches to increase messaging around the appropriate role of caregivers within Hawai‘i’s diverse communities.
4. Workforce Development workgroup to examine the public health field and assess the need for continuing education and training in dementia and brain health, and specific topics and content needed.

Hawai‘i’s target populations for health impact are all persons statewide at risk for or who have ADRD, as well as their family caregivers. Hawai‘i will implement strategies in the Hawai‘i 2035: State Strategic Plan on ADRD that addresses all areas of primary, secondary, and tertiary prevention, and includes those with an identified high burden of ADRD. Nearly 26% of Hawai‘i’s population is limited English proficient (LEP), and among those, 48% report speaking English less than “very well.” Asian American, Native Hawaiian, and Pacific Islanders (AANHPI) make up 82.5% of Hawai‘i’s population; Filipinos represent the largest AANHPI subgroup (14.9% of the state’s total population) and are the fastest growing population in the state. People of Japanese ethnicity are the largest non-white ethnic group in the 65 and over category.

In 2021, EOA contracted with Papa Ola Lōkahi, a Native Hawaiian health agency focused on improving Native Hawaiian health and well-being, to develop a Native Hawaiian Road Map on the Impacts of Alzheimer’s Disease and Other Dementias based on the Healthy Brain Initiative. Recommendations developed in this Road Map will also be included in our implementation plan. It is the first-ever public health guide focused on dementia in Native Hawaiians funded by CDC. It is modeled after the 2019 Healthy Brain Initiative Road Map for Indian Country focused on American Indian and Alaska Native communities.

The Hawai‘i 2035: State Strategic Plan on ADRD includes goals, detailed strategies, and action steps that were developed over two years by local stakeholders: the Hawai‘i’s CDC BOLD planning grant advisory committee and 4 workgroups which align with the CDC brain health road map actions. The most recent stakeholder review of goals was in February 2023. An evaluation indicated that, across both the advisory committee and workgroups, the majority of stakeholders reported each topic area they were involved in was important to them or their organization. Additionally, stakeholders shared which goals aligned with their or their organization’s interests, which goals they believed were more feasible than others, and ideas on how to realize the goals on a statewide level. This valuable feedback will be integrated into the development of the ADRD implementation plan.

The Hawai‘i 2035: State Strategic Plan on Alzheimer’s Disease and Related Dementias was presented to the community and posted on the Hawai‘i ADRC website during August 2023. Community members were able to provide feedback, in-person, by video conference call, online survey, email, and mail. See Appendix G for more detailed information. Many of the comments were incorporated in the plan’s narrative and some comments will be presented to the workgroups to consider for implementation.

This plan is the culmination of goals, strategies, and action steps that emerged from the discussions of four workgroups of the CDC BOLD Hawai‘i project, advisory committee, staff research, community outreach, and the Native Hawaiian Road Map funded by the CDC Planning Grant. It is a “living document” that will evolve through further research, outreach, engagement with existing and new stakeholders, and will respect our diverse cultures with equity, inclusion, and aloha.



## You Are My Sunshine: A Personal Story About Grandma

by Katsumi Takemoto



Grandma was born in 1911 in Honolulu's Chinatown and attended Kauluwela Elementary School. After school, she walked over to Fort Gakuen Japanese Language School. However, her formal education ended in the eighth grade when she was sent to Jigozen, Hiroshima, to help relatives. She stayed there for four years before returning to Honolulu. It was rare for her to speak about her past, but she mentioned playing baseball and admiring her brother who was a captain for the Keio University team in Japan playing with "The Babe," Babe Ruth. She also shared a poignant moment when she saw smoke rising during the bombing of Pearl Harbor from where she stood at Pacific Heights.

In the early 1980s, we experienced the sudden loss of ojiichan (grandfather) due to pneumonia. A few years later, I found Grandma with dried blood under her eyeglass nose pads. When I asked her what happened, she usually chuckled as she spoke and said, "I don't know." That's when I realized we had entered a new chapter, and I began my new role as a "caregiver" because Grandma started experiencing ongoing mini strokes.

There were not many services for kūpuna in the 1980s. There was no internet and I used the telephone book to search for help. I found Project Dana and the Honolulu Gerontology program, which provided invaluable companionship and social work support for Grandma. As things happen in sets of waves, one afternoon Grandma said in a composed tone, "I forgot how to cook rice." The statement was shocking, but I tried not to react. With that, something told me to check her pill organizer, where I found markings from bugs that had eaten through the pills — signs that they were left untouched for quite some time. Following our intuition as an antenna helps to guide our next steps.

While keeping up with my work duties, I cherished every moment with Grandma living with me. On my workdays, I would wake up extra early to ensure Grandma was stable, and hygiene cared for. Bathing Grandma every night I felt was a treat. When my son was a toddler, he would scrub her back with his tiny hands, which instantly soothed her. Although youth programs were not intergenerational yet at the time, we included my grandmother in programs that my son attended. I believe her presence in these activities, even as her health declined, brought a sense of richness that served as an example of lifelong learning for all.

When Grandma's dementia worsened, I began to dance and sing to her to transform the negative space into a positive one. Not that I was not listening, because I could ascertain when she repeated due to dementia and when she repeated because she was trying to say something. It seems simple



yet complex because I missed Grandma taking care of me. I don't know how to dance. But I believed it was important to transform dementia to dance and song. I turned my adult serious face to remember my childhood being, to be free as if nobody watched — jiggle your hips and dance, dance, dance!

There were always signs along the way with twists and turns. Grandma said she forgot how to get into my car. My neighbor saw us and ran over to help me carry her into the car, and my neighbor began to tear. I knew something changed, but there were no medical symptoms. Instinctively I drove straight to the ER. Even with no signs of cough or fever, she was diagnosed with pneumonia. She was admitted to the hospital and it was the last time she lived at home.

The doctor recommended that Grandma transition to a long-term facility. I continued to take her out to my son's activities, anywhere a wheelchair could go. At the end of her life, Grandma repeatedly sang "You Are My Sunshine" over and over. I believe she knew that when skies were grey, there was a rainbow nearby.

On her final night, at 1:25 a.m., I jotted down what I told her: "Grandma! Soon you will be with your mom and dad again! Ojichan, classmates... they're all waiting for you! You can walk and run again. You won't be alone. Can you feel your feet and legs get stronger? Everything is perfect, everything is okay, Grandma!"

After her last breath sometime later, with her body so still, amazingly, I saw her smile with a shining grin. It was the smile that was familiar to me when she used to care for me and everyone around her.

As we support our friends and loved ones, take calm breaths, and reflect on your first touch with your loved one. Where was your favorite place together? Now beyond words, your loved one is still experiencing lifelong learning. Remember, dementia teaches us to dance, dance, dance, expressing love beyond sight. Cherish each moment spontaneously. Share with others how you feel with your tender loving care. You are never alone.



## Creating an Inclusive, Dementia-Friendly Garden

**H**o'ola 'Āina Pilipili is an educational initiative at the University of Hawai'i at Mānoa College of Education centering 'āina-based learning, healing, and 'Ōiwi leadership in educational spaces. The phrase ho'ōla 'āina carries the meaning of regenerating life or growth. Pilipili is the traditional name of the 'ili (land division) that the UHM College of Education and University Laboratory School sit upon. The design of the garden site is inclusive for older adults and people with disabilities, featuring wheelchair accessible mats, wide pathways, vertical and raised garden beds, seating, shade, and local,



culturally relevant plants for food, teas, and medicine. This garden space is an example of gardens that are designed to be accessible for all, and future efforts will focus on including dementia-friendly features so the garden can be enjoyed by people with dementia and their caregivers. Everyone should feel welcomed in a healing space such as a school or community garden regardless of ability. Ho'ola 'Āina Pilipili is an age-friendly, accessible school community garden and 'āina learning center where we host school groups, professional development for educators, and community workshops on 'āina-based learning, Native Hawaiian crops and medicine, and accessible gardening basics. Visit the website at [sites.google.com/hawaii.edu/hoolaainapilipili](https://sites.google.com/hawaii.edu/hoolaainapilipili).

To learn more, email Melody Halzel at: [mhalzel@hawaii.edu](mailto:mhalzel@hawaii.edu).



# ADRD STATE STRATEGIC PLAN GOALS

*The Hawai‘i 2035: State Strategic Plan on Alzheimer’s Disease and Related Dementias will be a blueprint to address the challenges individuals with ADRD and their families are facing. This next section, ADRD State Strategic Plan Goals, will present the goals, strategies, and action steps developed by the four workgroups.*

## DATA

### I. Introduction

Data reflective of the experiences of Hawai‘i’s populations will be gathered and used to monitor and evaluate the progress of dementia capability in our state. Aligned with the CDC and the Alzheimer’s Association’s Healthy Brain Initiative action item to Monitor and Evaluate, we will “use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.”



### II. Vision Statement

To increase the utilization of available data and develop data sources that would allow for increased understanding of community achievements and where ADRD public health burdens exist, facilitated evolution of initiatives, and overall sustainability of activities over time.

### III. Current Data Sources

In 2019, an ADRD Data Advisory Team was established. EOA and COA (Center on Aging) partnered with the Telecommunications and Social Informatics Research Program/Pacific Health Informatics and Data Center (TASI/PHIDC) group at the University of Hawai‘i. The TASI/PHIDC group analyzed the Hawai‘i-specific All-Payer Claims Database, which includes Medicare data for disease prevalence, healthcare services utilization, and costs.

Additionally, standardized dementia screening was added to the ADRC in-home assessment tool. In particular, ADRC staff utilize the validated Mini-Cog and AD8 with clients who express memory concerns. The in-home assessment data, with the expanded dementia screening, can provide a larger picture of the demographic characteristics, health and social needs, and services provided to clients with memory loss.

In 2023, EOA also purchased the Cognitive Decline and Caregiver modules of the Behavioral Risk Factor Surveillance System (BRFSS). These modules are part of the Centers for Disease Control’s national survey that collects state-level data on health-related risk behaviors, chronic health conditions, and use of preventive services. The Hawai‘i BRFSS program remains committed to health equity as they continue to collect data by Hawai‘i-specific ethnicities, persons with behavioral health disorders, LGBT, low socioeconomic status, and communities with disproportionately higher levels of disease.

## IV. Gaps & Challenges

Gaps and challenges remain in the effective use of data to better understand where ADRD public health burdens exist. Hawai‘i is an ethnically diverse state and yet disaggregated data for the AANHPI population is limited, especially regarding prevalence of ADRD. In addition, AANHPI representation in federally funded research is severely lacking, with AANHPI populations making up just 1% of study populations.<sup>41</sup> Hawai‘i’s diverse cultural and ethnic environment can be a laboratory for studies unique to Hawai‘i, which could contribute to the growing worldwide body of research.

Hawai‘i will seek to expand and support local research efforts, as well as to identify and utilize new sources of data (e.g., from health systems) to keep Hawai‘i healthcare professionals and the public informed in a timely manner on the most current dementia research on effective prevention and treatment of dementia, both nationally and worldwide.

## V. Goals, Strategies, & Action Steps

### GOAL I.

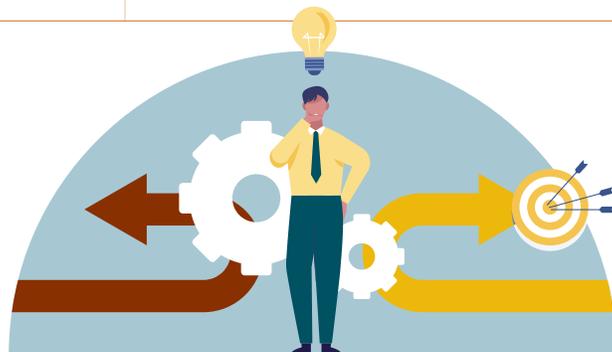
Build statewide and national networks to contribute to the science and understanding of ADRD in Hawai‘i’s diverse communities worldwide.

STRATEGIES	ACTIONS
<p><b>1.</b> Develop a Hawai‘i research consortium to expand research and programs unique to Hawai‘i.</p>	<p><b>1a.</b> Build relationships with national research partners.</p> <p><b>1b.</b> Convene a local dementia symposium and panel sessions.</p> <p><b>1c.</b> Share the latest information about promising research and interventions with Hawai‘i healthcare professionals, as well as the general public, through educational events, online sources, and the media.</p>
<p><b>2.</b> Ensure ADRD-relevant data is made accessible and meaningful to all networks and stakeholders.</p>	<p><b>2a.</b> Include data resources in the publicly accessible central repository for ADRD resources and state plan materials to be housed on a designated section of the EOA website.</p> <p><b>2b.</b> Create EOA dementia-focused initiative to facilitate annual updates to the resources and materials housed in the repository.</p> <p><b>2c.</b> Develop and advocate for the usage of collection techniques that promote the disaggregation of data to adequately capture statistics on minoritized populations.</p>
<p><b>3.</b> Support and aim to leverage funding for the piloting of new research and programs.</p>	<p><b>3a.</b> Leverage funding from local, state, and national sources to support pilot programs.</p> <p><b>3b.</b> Promote AANHPI representation in research by enrolling AANHPI populations in research registries (i.e., CARE– Collaborative Approach for Asian Americans and Pacific Islanders Research and Education).</p>

## GOAL II.

Use data effectively for continuous quality improvement and to inform providers, program development, and policy.

STRATEGIES	ACTIONS
<p><b>1.</b> Continue to leverage current data sources by collaboration within established partnerships.</p>	<p><b>1a.</b> Secure funding for the administration of the next round of cognitive decline and caregiver modules in the administration of the Hawai'i Behavioral Risk Factor Surveillance Survey (BRFSS).</p> <p><b>1b.</b> Maintain collaboration with UH TASI (Telecommunications and Social Informatics Research Program), All-Payer Claims Database, and Alzheimer's Association - Hawai'i Chapter to continue to analyze service utilization and costs by comparing the ADRD population and the non-ADRD population. Utilize updated data as available (updated Medicare, Medicaid, dual eligible data).</p> <p><b>1c.</b> Formulate data use agreements with collaborators to be renewed after a period of 5 years.</p>
<p><b>2.</b> Identify opportunities for new and improved data collection and analysis on ADRD in Hawai'i.</p>	<p><b>2a.</b> Continue to identify opportunities to collaborate with agencies and organizations that have an interest in developing a better statewide surveillance system for dementia.</p> <p><b>2b.</b> Collaborate with partner agencies on how to supplement gaps in data and identify additional data sources to better understand the needs and issues of persons living with dementia, including: ADRD within Hawai'i's Medicaid population, family caregiver costs, out-of-pocket ADRD expenses, quality of care and quality of life for the patient and care partners, and stress and well-being of ADRD families. This includes collecting and integrating ADRD-relevant SAMS (Social Assistance Management System) and external DOH data into overall evaluation of service delivery.</p> <p><b>2c.</b> Expand partnerships for primary data collection from persons living with dementia and their care partners. Encourage participation from those underrepresented in research and identified by the Public Awareness &amp; Education workgroup (i.e., AANHPI).</p>



### GOAL III.

Use data and evaluation to monitor progress on the implementation of the state plan and set new goals to further Hawai'i's dementia capability.

STRATEGIES	ACTIONS
<b>1.</b> Create a data tracker to monitor progress on the implementation of the state plan and set new goals to further Hawai'i's dementia capability.	<b>1a.</b> Consult with appropriate entities to develop and maintain a publicly facing data tracker instrument incorporating BRFSS and external data sources. <b>1b.</b> House tracker in a designated ADRD section of the EOA website. <b>1c.</b> Develop indicators based on the strategies in the four workgroups into the data tracker for monitoring purposes. <b>1d.</b> Pursue continuous funding for developing and maintaining a data tracker. <b>1e.</b> Monitor and refer to national programs and policies, as well as local programs employing best practice models to check on relevance and meaningfulness of identified indicators. <b>1f.</b> Perform a semi-annual look-back in SAMS data to uncover quality issues relevant to ensuring proper procedure for diagnosis, treatment, and referral. This will need to be addressed by EOA through policy and procedure creation.
<b>2.</b> Review ADRD State Plan progress based on indicators identified in the strategies on a semi-annual basis.	<b>2a.</b> Maintain a stakeholder advising body to convene semi-annually with ADRD Coordinator and designated EOA staff or consultants for this review.
<b>3.</b> Incorporate stakeholder voices in the evaluation process.	<b>3a.</b> Gather ongoing first hand qualitative information to monitor progress through surveying and conducting interview or focus group activities with persons living with dementia and their families.
<b>4.</b> Disseminate quantitative and qualitative data effectively to inform providers, program development, and policy.	<b>4a.</b> Develop an annual policy brief on the Statewide ADRD profile and services prepared before the start of the legislative session which includes updates from the other three workgroups.
<b>5.</b> Look for ways to collect data from new sources and analyze impact.	<b>5a.</b> Keep abreast of local, national, and international ADRD initiatives, work plans, and research to generate data and analyze ideas relevant to the Hawai'i ADRD State Plan.

## The Care Team Approach Helped When Needed: A Personal Story

by Drusilla Tanaka

After Kazue (Kawamoto) Tanaka's husband passed away in June 1986, she lived on her own, managing her finances, preparing and filing her annual tax returns, walking or using the bus for transportation in Kailua or to Chinatown for flowers to decorate the graves of her husband and other family members.

In 2008, she moved in with us into her own living area, and she easily adjusted, including learning how to take the bus from our house in Kaneohe to her senior clubs, classes, and congregate dining site in Kailua — surprising, but celebrated nevertheless. She insisted on being independent, wanted her own phone line, TV cable, and daily newspaper. She shopped for her own fresh fruit and bread and made her own breakfast of toast with peanut butter and jelly and papaya. Lunch was at the meal site, while we took care of supper and weekend and holiday meals.

A dramatic event that occurred without our knowledge: Kazue decided on her own to close her bank accounts, canceling direct payments to her cable, phone, newspaper, and so forth. We discovered this because she presented us with a check issued upon closing her savings and checking accounts and asked us to take care of it. After we learned what happened, we quickly opened a new account at a different bank with my husband as joint owner and arranged for automatic payments and direct deposits.

I also called her bank and spoke with the manager regarding the sudden closing of the accounts, but there was nothing that could be done to restore the account. I believe she was 88 years old at the time. She had been a long-time client, so they may not have noticed subtle changes in her behavior. I hope banks have since developed procedures to address what happened in Kazue's case along with the stress we endured.

Shortly after moving here in 2008, I began to accompany Kazue on her regular doctor visits. She would often say to us, "Oh, I cannot remember..." or something similar, which I reported to her doctor. She began medication for her short-term memory loss which was confirmed by a "test" in the doctor's office. She moved up the medication ladder and was last on Exelon. She did not exhibit the common signs of dementia patients, such as repetitive language, getting lost, inability to learn something new. She also did not register any pain. She was usually very pleasant and playful and always grateful. I used to say to her caregivers that "Kazue has an overabundance of 'happy hormones.'"



As her impairment progressed, she began to display what we thought was "bizarre" behavior, especially at the dinner table during family dinners, such as removing her dentures and cleaning them, blowing her nose into her napkin, burping, and passing gas. Her behavior reminded me of a very young child, and I wondered if it was "normal" behavior for persons with dementia. She began to refuse bathing, showering, shampooing, insisting that she already completed her bath.

During this time, she continued to attend daily senior activities/congregate dining and travel by city bus. When the congregate dining site moved, the program arranged for Handi-Van service to the new location. The challenge for the drivers was to be sure her seat belt was securely fastened at all times, as she would randomly release it.

When the congregate dining site closed completely "due to lack of funding," she just stayed at home. After a few weeks, she seemed low-energy, perhaps lonely. She began asking for just a quarter of a papaya and "not too much" food. We realized that she needed social interaction and other stimulation, as reading the paper and watching television were not enough.

When her doctor suggested Ensure to increase her weight (88 pounds), we began to sit with her to be sure she was not throwing her food away. Mealtime was no longer a pleasant experience with my husband scolding her for just moving her food around the plate.

Fortunately, she was able to enroll in adult day care in Kailua. Day care staff reported that she was always pleasant and cooperative. However, the daily battles at home with bathing, eating, getting up and ready to leave for day care were wearing us down.

We were so fortunate to be able to hire caregivers from Good Samaritan Society (GSS) Services@Home. A caregiver would arrive at 7:30 a.m. to be sure she was up, dressed, ate breakfast, toileted, and ready to go. The caregiver would drive her to day care. In the afternoon, a caregiver would pick her up at day care, drive her home, assist with her bath, dinner, play cards or watch TV and have a snack together. The caregivers reported no negative behavior such as arguing or stubbornness. Instead, they enjoyed working with her!

Having friendly, caring personnel on a daily basis brought peace back into our household. This arrangement continued until she suffered seizures at home in 2019 while reading the newspaper. After a short stay in the hospital for observation and testing, she was placed in an adult foster care home, as it was determined she needed skilled nursing care. Given the invaluable support these care personnel provide, we hope there continues to be rules and regulations developed to support the services they provide.

Kazue made a good adjustment and gained weight. We celebrated her 100th birthday during COVID-19 in the carport of the care home with masks on. Kazue passed away in 2022 under hospice care, just shy of her 102nd birthday.



# PROGRAM & POLICY CHANGE

## I. Introduction

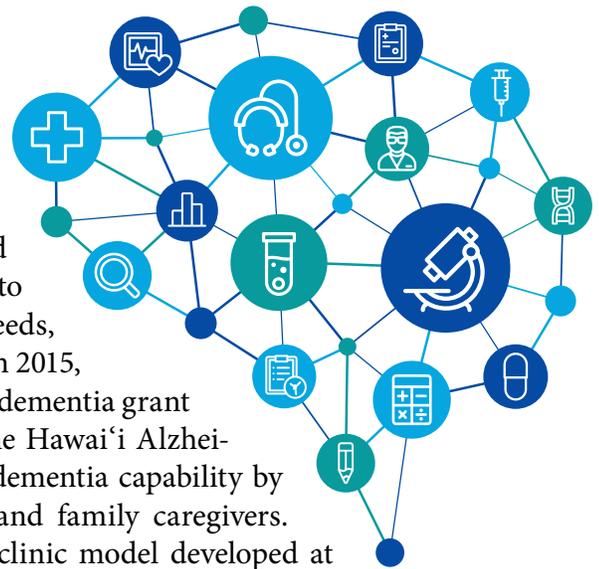
Further development of evidence-informed programs and supportive policy is needed to build upon the existing clinical and community-based dementia care infrastructure. Aligned with the CDC and the Alzheimer’s Association’s Healthy Brain Initiative action item to Develop Policies and Mobilize Partnerships, Hawai‘i will “promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia.”

## II. Vision Statement

To develop integrated and dementia-capable systems in Hawai‘i.

## III. Current Context

Statewide efforts have strengthened quality and efficiency of care and support for persons with ADRD. Three federal grants have enabled Hawai‘i to pilot and evaluate evidence-based and best practice programs and approaches. Training provided to healthcare professionals and family caregivers address critical needs, particularly in the areas of awareness and knowledge of ADRD. In 2015, the University of Hawai‘i Center on Aging (COA) was awarded a dementia grant from Administration for Community Living (ACL) to create the Hawai‘i Alzheimer’s Disease Initiatives (HADI). The grant took steps toward dementia capability by providing training to health professionals, paraprofessionals, and family caregivers. Through COA’s cooperative agreements with ACL, a memory clinic model developed at Kokua Kalihi Valley (KKV), a federally qualified health center (FQHC), is being replicated within three other FQHCs and within one senior center (Lanakila Multi-Purpose Senior Center). HADI developed a memory care navigator model, based on national best practices, that was implemented by public health nurses and Project Dana volunteers. The memory care navigator model promotes early screening and identification, education, and connections to community resources. The federal grant also implemented the evidence-based Savvy Caregiver program in Hawai‘i, a psychosocial program designed to improve the practical skills of dementia caregivers. Hawai‘i’s Savvy Caregiver program is championed by two trainers — Dr. Lucas Morgan, clinical psychologist, and Dr. Poki‘i Balaz, advanced practice registered nurse.



In 2017, EOA received a 3-year federal ACL grant to train state agencies in the No Wrong Door Network to ensure that staff are dementia capable. The core concepts covered by the training included: 1) basic dementia capability, specifically distinctions between normal aging and dementia, treatments, and communication strategies; 2) the use of the AD8 Dementia Screening Interview (AD8) and Mini-Cog screening tools to promote early detection; and 3) special topics including non-pharmacological strategies to manage behavioral challenges, end-of-life care, and dementia with intellectual and developmental disability populations. Staff are able to administer cognitive screening tools and make appropriate community referrals to memory care services. In coordination with HADI, this grant also streamlined referrals from state agencies to community memory care resources, including memory clinics, memory care navigators, the Savvy Caregiver program, and the Alzheimer’s Association-Hawai‘i. This funding enabled the continuation and expansion of the Savvy

Caregiver program to other parts of the state and enabled EOA to improve transitions of care of patients with dementia from hospital to home through pilot projects at Straub and Pali Momi hospitals.

Another key objective of the grant was to empower families with the knowledge to navigate the long-term care system and connect to valuable memory care resources. Finally, the grant created a Memory Care Roadmap for Family Caregivers with both local and national dementia resources (see Appendix B).

In 2019, Catholic Charities Hawai‘i (CCH) received federal funding from the ACL to create the Hawai‘i Circle of Care for Dementia. One grant objective is to implement the evidence-based REACH program, an educational program to improve the knowledge and skills of dementia caregivers. Another objective is to pilot outreach and engagement strategies to culturally diverse faith-based communities through the Dementia Friends program. The grant also intends to reduce the silos between aging and disability systems through targeted education to people with I/DD who are disproportionately affected by ADRD. CCH is improving ADRD screening for people with I/DD by providing training to use the National Task Group (NTG) Early Detection Screen for Dementia (NTG-EDSD). See call-out box on page 59 with an update on CCH’s new grant award.

Another effort connected Hawai‘i to a global initiative to reduce the stigma around dementia by creating dementia-friendly communities. Dementia Friends Hawai‘i, part of Dementia Friends USA and connected to Dementia Friends programs in other parts of the world, is a public engagement initiative that aims to provide education and build dementia-friendly communities (See call-out box on page 33). With funding from the National Asian Pacific Center on Aging (NAPCA), Dementia Friends Hawai‘i also collaborated to translate and pilot Dementia Friends with Chinese and Samoan churches on O‘ahu.

Finally, community organizations continue to champion aging and dementia education. Positive Approach to Care® (PAC) trainings have been offered statewide and led by Dorothy Colby, certified trainer and Director of Community Engagement at Hale Kū‘iike, an adult residential care home specializing in memory care. Teepa Snow’s PAC is an internationally recognized dementia education and advocacy organization that promotes a more positive and competent dementia care culture. Its robust offerings of in-person and virtual events, products, and training opportunities enhance awareness, knowledge, and skills of organizations, direct-service providers, and informal caregivers so they may provide quality and compassionate care that respects the dignity and retained abilities of people living with dementia while simultaneously lessening the stress and frustration of their care partners. Through its work, PAC fosters an inclusive global community that sees dementia as a manageable disability, and not an immediate death sentence. Another valuable training series, *Dealing with Dementia*, has been offered by Hale Hau‘oli Hawai‘i with support from the Rosalynn Carter Institute of Caregiving. The training series focused on understanding dementia, addressing problem behaviors, and managing stress. Hale Hau‘oli Hawai‘i followed up with another series of workshops called “Dementia in the Family,” which covered caregiving, legal, and stress management issues. Lastly, Generations Magazine’s Aging-in-Place conferences are visible and well attended events that include dementia presentations.

#### IV. Gaps & Challenges

In 2018, the Alzheimer’s Association held a statewide series of community forums which revealed updated insights into the unique challenges facing Hawai‘i’s rural care partners and persons with dementia. In particular, the following were key lessons learned: 1) transportation continues to be a significant barrier in rural communities; 2) neighbor island communities were very interested in web-based education and telehealth (for their providers); and 3) after a 45-minute educational on program on the basics of Alzheimer’s and dementia, most participants were not confident in their understanding of the disease.

## V. Goals, Strategies, & Action Steps

### GOAL I.

Encourage statewide availability and utilization of early detection and regular screening methods.

STRATEGIES	ACTIONS
<p><b>1.</b> Collaborate with community providers and organizations statewide to establish dementia capability in staff and support their ability to perform early detection and regular screening.</p>	<p><b>1a.</b> Conduct outreach, build relationships with community gatekeepers, and ensure that early detection and screening is integrated within an organization’s workflows and protocols.</p>
<p><b>2.</b> Strengthen existing or establish new partnerships to enhance screening and early detection capacity in the No Wrong Door (NWD) network.</p>	<p><b>2a.</b> Align with EOA’s plan for expansion of No Wrong Door (NWD) network and work with organizations and agencies that are being onboarded in order to ensure their dementia capability.</p> <p><b>2b.</b> Further integrate dementia capability into the training of new No Wrong Door organizations and agencies.</p> <p><b>2c.</b> Train new No Wrong Door agencies and organizations in making online referrals of persons with memory loss or dementia.</p> <p><b>2d.</b> Integrate dementia information and capability training into existing DOH chronic disease initiatives with risk factors to ADRD.</p>
<p><b>3.</b> Promote continuing education and training in dementia capability so that they are widely available within Hawai‘i’s aging network, including healthcare and long-term care providers.</p>	<p><b>3a.</b> Provide training on how to respond to cognition screening scores consistent with dementia or indicating memory loss, and navigating the healthcare continuum, and making recommendations to memory care resources statewide.</p> <p><b>3b.</b> Deliver specialized training on high need topics, such as but not limited to behavioral challenges or delirium.</p> <p><b>3c.</b> Continue to expand the implementation of dementia training to other state and city sectors outside of medical professions. (i.e., first responders and transportation providers).</p> <p><b>3d.</b> Piggyback on existing DOH chronic disease education initiatives with risk factors relevant to ADRD.</p>
<p><b>4.</b> Promote public awareness of Medicare coverage for cognitive assessment and testing as part of yearly wellness visits.</p>	<p><b>4a.</b> Integrate information on cognitive assessments as part of annual Medicare wellness visits (i.e. conducted by Primary Care Physicians, internists, family medicine, and geriatricians) as part of our ADRD State Plan awareness campaigns.</p> <p><b>4b.</b> Partner with health plans and provider organizations to encourage widespread use of cognitive assessment and testing annually with all older patients.</p>

The concept of the No Wrong Door system is that no matter what “door” (agency) you call, you will be referred to the right “door” who will be able to help you and your family.

## Dementia Friends Hawaii

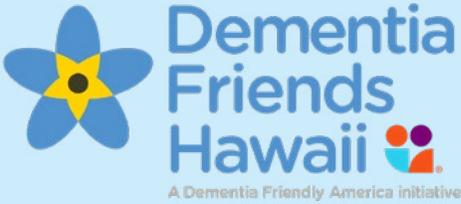
Dementia Friends Hawaii is part of a global movement to educate community members from different sectors about dementia and how to help those with dementia. The program is a partnership between Age-Friendly Honolulu and the UH Center on Aging’s Hawai’i Alzheimer’s Disease Initiative. As part of the Dementia Friends information session, attendees pledge to become a “Dementia Friend” and pledge to take action within their family or community. Dementia Friends Hawaii has been targeting different sectors in the community, including libraries, financial sectors, senior groups, churches, and schools. Mānoa



Cottages in Kaimuki and Mānoa have trained their staff in the Dementia Friends curriculum. The initiative has expanded from O’ahu to Kaua’i, where it has been embraced by the Mayor and county directors. Dementia Friends Hawaii has educated student groups, banks, libraries, and senior groups on how to better communicate with and support persons with dementia. To date, Dementia Friends Hawaii has offered over 60 educational sessions and reached more than 2,000 individuals.



For more information, visit: [dementiafriendsusa.org](http://dementiafriendsusa.org) or [www.hiphi.org/age-friendly-honolulu](http://www.hiphi.org/age-friendly-honolulu)



## GOAL II.

Promote informed, coordinated care and services for persons living with dementia.

STRATEGIES	ACTIONS
<p><b>1.</b> Develop an accessible hub for dementia resources.</p>	<p><b>1a.</b> Update and maintain an accessible inventory of statewide memory care organizations and programs for use among the NWD (No Wrong Door) and aging network.</p> <p><b>1b.</b> Develop and categorize a repository of dementia educational flyers and brochures accessible and meaningful to persons living with dementia, caregivers, and providers in the NWD and aging network.</p> <p><b>1c.</b> Create an ADRD section of the EOA website accessible to all stakeholders that stores an inventory of dementia care programs and a repository of dementia educational materials.</p> <p><b>1d.</b> Continue and expand partnership with the State Library System. Initiatives could include the creation of a brain health and dementia resource section in each library along with establishing memory cafés and activities at library sites.</p>
<p><b>2.</b> Promote and implement an interdisciplinary, team-based approach that supports persons living with dementia and their families in both institutional and community settings.</p>	<p><b>2a.</b> Identify, expand, and put into practice evidence-informed models of inpatient care, residential safety, and care transitions for people with cognitive impairment.</p> <p><b>2b.</b> Evaluate current care transition programs statewide to identify best practices and lessons learned that can be adopted by other health systems.</p> <p><b>2d.</b> Increase collaboration between health, social service, and legal service providers to support coordinated and safe transitions to supportive housing options.</p> <p><b>2e.</b> Encourage professional care planners to be person-centered and integrate the needs, perspectives, and insight of persons living with dementia and their family members.</p>

## GOAL III.

Advance risk reduction and brain health awareness and education.

STRATEGIES	ACTIONS
<p><b>1.</b> Develop a culturally responsive public awareness campaign on brain health. (See Public Awareness &amp; Education strategies for targeted cultural groups.)</p>	<p><b>1a.</b> Engage partner organizations working with populations disproportionately affected by risk factors for ADRD.</p> <p><b>1b.</b> Align strategies for targeted cultural groups.</p> <p><b>1c.</b> Leverage available sources of funding from federal, state, and local sources and coordinate with community partner organizations to develop and manage campaign efforts.</p>

STRATEGIES	ACTIONS
<p>2. Utilize community events and spaces to educate the public on brain health and promote early detection of cognitive impairment.</p>	<p>2a. Organize trainers to participate in general health events, community gatherings, and fairs.</p> <p>2b. Identify and partner with community agencies not traditionally associated with healthcare (e.g. arts, retail, agriculture, hospitality, and food and beverage industries, etc.) to provide education, develop new programming, and promote dementia-friendly spaces (e.g. museums, restaurants, agriculture, etc.).</p>
<p>3. Demonstrate linkages between brain health and common risk factors across chronic diseases.</p>	<p>3a. Collaborate with DOH Chronic Disease Prevention &amp; Health Promotion Division to provide timely and accurate messaging on dementia and relevant risk factors to a wider public audience.</p>

## A New Beginning



by Tony S. Vericella

Five years ago, my wife of 38 years was diagnosed with early onset dementia. We are long past the beginning. Together, our family is accepting that the Dana we knew would live on mostly in our memories. We wait for moments, even seconds, of recognition, of love, of reassurance that she is not suffering. And we plan — how do we take this pain, learn from it, and prepare others? And now, there is a new beginning, a beginning that has purpose — helping the thousands of families that wake up daily to the realization their loved one is slipping away, regressing into an unknown void where their shared memories are no longer a source of comfort or joy. My family is not alone — millions of families fall victim to the indiscriminate ravages of

Alzheimer’s disease each year. The effects of the disease impact not only the person diagnosed, but everyone around them. How can we make sure that no family is forced to face Alzheimer’s alone? My goal is simple — to pass on the healing, the strength, and the power that comes from understanding and sharing experiences. My mission for our non-profit, Alzheimer’s Caregiving & The Caregivers, is to prepare, equip, and provide evolving support to families and friends caregiving for loved ones diagnosed with the progressive and debilitating effects of Alzheimer’s disease and related dementias. Visit [www.alzcaregiving.org](http://www.alzcaregiving.org) for resources curated and organized to help with caregiving and to support caregivers. Email: [contact@alzcaregiving.org](mailto:contact@alzcaregiving.org).



ALZHEIMER’S CAREGIVING  
♥ & THE CAREGIVERS ♥

**GOAL IV.**

Promote the use of effective interventions and best practices to protect brain health and address cognitive impairment for persons living with dementia.

STRATEGIES	ACTIONS
<p><b>1.</b> Stay up-to-date on national goals and best practices in brain health and risk reduction.</p>	<p><b>1a.</b> ADRD Coordinator and designated EOA staff or consultants to stay updated on current research and educational materials by attending national trainings and presentations on brain and cognitive health, and subscribing to pertinent mailing lists.</p> <p><b>1b.</b> Continue to monitor and incorporate information on services and interventions supporting brain health and cognitive well-being into state plan updates.</p>
<p><b>2.</b> Add brain health messaging to existing health promotion programs.</p>	<p><b>2a.</b> Engage with DOH and community services stakeholders that promote individual well-being and identify points of synergy with current brain health information.</p> <p><b>2b.</b> Integrate brain health information within current DOH prevention messaging.</p>
<p><b>3.</b> Expand availability of culturally relevant diet and nutrition resources.</p>	<p><b>3a.</b> Develop opportunities to teach about the MIND diet and how to cook brain healthy foods.</p> <p><b>3b.</b> Convene culinary practitioners to develop brain healthy recipes and meal plans that are aligned with the MIND diet and are culturally tailored.</p> <p><b>3c.</b> Integrate brain healthy meals into congregate and home delivered meal services.</p>
<p><b>4.</b> Re-imagine senior center/club programming through a brain healthy lens.</p>	<p><b>4a.</b> Work with community partners and client stakeholders to develop and implement brain health programs that have meaningful content.</p>



## GOAL V.

Provide adequate and timely support for caregivers of persons living with dementia.

STRATEGIES	ACTIONS
<p><b>1.</b> Build upon the successes and lessons learned from the current evidence-based and evidence-informed dementia caregiver programs in Hawai‘i.</p>	<p><b>1a.</b> Identify opportunities to scale and sustain caregiver programs provided by community partners.</p> <p><b>1b.</b> Research emergent best practices in dementia caregiving that could be meaningful to implement with local populations.</p> <p><b>1c.</b> Support the continued implementation of caregiver services with state funds.</p>
<p><b>2.</b> Continue to identify and promote programs and policies that engage and empower caregivers and support systems for people living with dementia.</p>	<p><b>2a.</b> Monitor developments nationwide and internationally to identify other evidence-based programs that can be translated/tailored to Hawai‘i’s communities.</p> <p><b>2b.</b> Provide information and tools to help caregivers for people living with dementia anticipate, avert, and respond to challenges that typically arise during the course of dementia.</p> <p><b>2c.</b> Continue to advocate for the expansion and wider availability of home and community-based services, including but not limited to affordable transportation, in-home support, adult day care, and respite programs.</p> <p><b>2d.</b> Provide advocacy training and support for caregivers.</p>
<p><b>3.</b> Enable Hawai‘i’s family caregivers and families to continue to provide care while maintaining their own health and well-being.</p>	<p><b>3a.</b> Promote the engagement of peer mentors who are experienced current or former caregivers to provide emotional and instrumental support to newer caregivers.</p> <p><b>3b.</b> Collaborate with labor organizations and employment entities to advocate for implementation of flexible work options for working caregivers that allow for both meaningful employment experiences and ability to attend to caregiving responsibilities.</p> <p><b>3c.</b> Provide education on current legal protections and allowances for working caregivers and advocate for further reasonable accommodation.</p> <p><b>3d.</b> Encourage outreach to and support of young professional caregivers.</p>
<p><b>4.</b> Better understand the intergenerational caregiving relationships that exist in local communities to recognize potential caregiving barriers for youth caregivers and grandparents raising grandchildren.</p>	<p><b>4a.</b> Work with community partners and stakeholders to understand the issues and needs of these populations.</p>

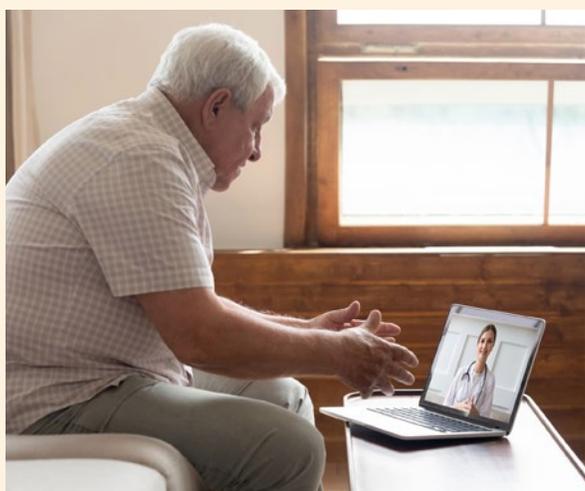
**GOAL VI.**

Encourage the dignity and safety of persons living with dementia.

STRATEGIES	ACTIONS
<p><b>1.</b> Improve safety for persons living with dementia at home, independently or with care partners.</p>	<p><b>1a.</b> Educate families on falls prevention, as well as offering home safety assessments, and how to monitor those that wander from home.</p> <p><b>1b.</b> Further develop policy increasing Hawai‘i’s crisis capacity for persons living with dementia who are having severe behavioral issues or caregivers who are burnt out or ill.</p> <p><b>1c.</b> Continue and expand the county level models for home safety assessments through collaboration with emergency responsive services.</p>
<p><b>2.</b> Build capacity to address an increasing number of behavioral crises that occur in patients with dementia.</p>	<p><b>2a.</b> Create a special workgroup to identify program and policy approaches to enhance training, and expand capacity of geriatric psychiatric and crisis services statewide.</p>
<p><b>3.</b> Develop policies and protocols for crisis situations and natural disasters inclusive of persons with various stages of cognitive impairment.</p>	<p><b>3a.</b> Examine the COVID-19 pandemic’s impact on how community-based services and supports are provided.</p> <p><b>3b.</b> Partner with local disaster preparedness organizations to develop clear Federal Emergency Management Agency (FEMA) guidelines for sheltering and supporting people with dementia and their caregivers.</p> <p><b>3c.</b> Enact policies and designed infrastructure to support persons living with dementia, to prevent wandering, and to help find missing people living with dementia or cognitive impairments.</p>
<p><b>4.</b> Maintain the dignity and rights of people with dementia and their caregivers across a broader spectrum of needs.</p>	<p><b>4a.</b> Partner with professionals (e.g., elder law attorneys, Kōkua Mau, health organizations, and community groups) statewide to offer presentations that cover dementia and legal issues, including advance care planning, power of attorney, and trusts.</p> <p><b>4b.</b> Work with fiscal agents to develop comprehensive financial planning for persons living with dementia and their families.</p>
<p><b>5.</b> Support the aging-in-place of persons living with dementia in single family homes as well as managed condos and rental properties.</p>	<p><b>5a.</b> Provide dementia awareness training for property managers and housing associations who have large numbers of older adults in their residences.</p> <p><b>5b.</b> Provide opportunities to finance home assessments and home modifications for single family households.</p>

STRATEGIES	ACTIONS
<p>6. Promote safety in medication management for persons living with dementia.</p>	<p>6a. Encourage the education and use of best practices in medication management techniques for persons living with dementia and caregivers.</p> <p>6b. Provide interdisciplinary training on medication management for ADRD to care teams supporting persons living with dementia.</p>
<p>7. Promote the availability and accessibility of dementia aids and assistive technology.</p>	<p>7a. Provide a listing of vetted resources through an online portal (e.g. monitoring programs/devices, modified telephones, GPS location and tracking devices, homecare robots, etc.).</p> <p>7b. Advocate for financial support for the acquisition of assistive technology (e.g. monitoring devices, comfort aids, hearing aids, assistance animals, etc.).</p> <p>7c. Stay abreast of cutting edge research and development in the area of technology and supports for aging in place.</p>

## Gerontechnologies May Help People with ADRD Age in Place



With sufficient informal supports (e.g., family, friends, neighbors, community volunteers) and formal supports (e.g., paid healthcare and social service professionals) working together as a coordinated team, older adults with some cognitive impairment, especially if mild or in the early stages, may be able to safely age in place at home as long as their care needs are adequately monitored, assessed, and addressed. Gerontechnologies (also spelled gerotechnologies) — which are technological products, services, and solutions geared to enhance the lives of older adults — can also play an important role in creating a safe and secure home environment.

The COVID-19 pandemic accelerated the increased use of personal, home-based technologies in healthcare and social

services. For example, telehealth allowed healthcare providers to communicate with patients through internet-based videoconferencing services and smart phones. While not all medical or social welfare appointments are suitable for telehealth, the options for care have expanded through the increased use of technologies. Telehealth also saves travel time and inconvenience, as well as unnecessary exposure to strangers in waiting rooms and service lines, for both patients and accompanying caregivers. With telehealth, healthcare professionals can “check in” with their patients, review test results, maintain and update medications lists, and document their interactions



on electronic medical records accessible to patients and their team of healthcare providers. (It also gives the providers a peek into patients' actual living spaces, which is not possible with the conventional office visit.) Patient-centered electronic medical records were already in development prior to the pandemic, of course, but their coordinated use with telehealth was particularly helpful during the pandemic.

In addition to telehealth, there are many different types of gerontechnologies that can be used in the home by older adults or their caregivers for health maintenance and safety, most notably Personal Emergency Response Services (PERS). These are digital communication devices that can be worn as a necklace, bracelet, or kept somewhere in the home in case of a real or perceived emergency when an immediate response is necessary. PERS can save lives if older people have an emergency when they are at home alone.



Other in-home health-related technologies include electronic pill and wellness reminders, fall detectors, motion and physical activity sensors, movement-triggered lighting, remote vital statistics collection for older adults with chronic diseases, mobile apps connecting older adults with their caregivers, other technologies for facilitating non-emergency communications and connectivity to resources and education, geofencing devices to alert caregivers to a wandering loved one, and voice-activated and other emerging



artificial intelligence technologies that can detect when a problem arises before it escalates to a crisis. Remotely controlled cameras have long been commercially available for home installation, but also raise privacy and other ethical considerations when used for surveillance of adult family members without their informed consent, especially inside the home in spaces where privacy is expected. However, they are increasingly being used for external surveillance as a crime deterrent and could be used to view who enters and leaves the property. Various assistive technologies can help older adults who are hearing impaired use the telephone (e.g., Telecommunications

Device for the Deaf) and the visually impaired use printed text materials (e.g., enlargers, braille and audio reading services, national newspapers read by computer over the phone).

The interdisciplinary field of universal design takes a related elder-friendly approach to home modification and pays particular attention to making an older adult's living space as safe and accessible as possible. The principles of gerontechnology, architecture, interior design, and home improvement converge to design customized living spaces for people with particular needs.

Some gerontechnologies may not be feasible for all older adults due to barriers such as cost, complexity, and personal preferences. However, when they "fit" with the needs, abilities, and desires of the older adult, they can add a layer of safety and security to aging in place, as well as possibly postpone placement to an alternative living environment.

If interested, older adults with some cognitive impairment and their caregivers should consult with qualified gerontechnology, healthcare, and home modification professionals about which technologies and interior designs would be most appropriate.

## GOAL VII.

Strive for diversity, equity, and inclusion in services and supports for individuals impacted by dementia.

STRATEGIES	ACTIONS
<p><b>1.</b> Partner with organizations and programs providing culturally based community services to develop and promote equitable and culturally responsive brain health practices for Hawai‘i’s diverse populations.</p>	<p><b>1a.</b> Integrate and implement indigenous, culturally relevant, and gender inclusive understandings of health and well-being into memory care programs and services.</p>
<p><b>2.</b> Improve care for populations in Hawai‘i who are disproportionately affected by dementia, and for populations facing care challenges.</p>	<p><b>2a.</b> Partner and coordinate with special populations such as those with Down syndrome, traumatic brain injury, the houseless and those living in poverty, residents of rural areas, those living alone, those living with early onset dementia, those with chronic health conditions, and different ethnic groups.</p> <p><b>2b.</b> Continue to identify populations disproportionately affected by dementia and its risk factors through working with partner agencies and work with key informants to develop outreach efforts tailored to these communities.</p>
<p><b>3.</b> Encourage the development and access to culturally responsive education, training, and support materials for Hawai‘i care partners and families.</p>	<p><b>3a.</b> Encourage the integration of culturally responsive information and materials into training modules that are made publicly available.</p> <p><b>3b.</b> Utilize relationships with stakeholders and community partners to create and disseminate culturally tailored approaches and implementation strategies.</p>
<p><b>4.</b> Strategically plan for the creation of more dementia friendly communities to address stigma associated with dementia.</p>	<p><b>4a.</b> Utilize the resources and strategies of Dementia Friends Hawaii to train champions and reach different sectors in our communities.</p>
<p><b>5.</b> Support the continued employment of persons living with dementia.</p>	<p><b>5a.</b> Engage employers, human resource departments, and unions to provide educational sessions and brain health materials for dissemination to employees.</p> <p><b>5b.</b> Advocate for the provision of brain health policy and education for members of chambers of commerce.</p> <p><b>5c.</b> Develop and implement training for employers to support employees experiencing cognitive decline.</p>

## GOAL VIII.

Elevate care planning for persons living with dementia at all stages to prepare for care across the life course.

STRATEGIES	ACTIONS
<p><b>1.</b> Promote the widespread usage of Advance Care Planning, primarily advance directives and POLST, through provider and family caregiver trainings.</p>	<p><b>1a.</b> Integrate education and training on use of Advance Care Planning, primarily advance healthcare directives and POLST, through primary care providers, specialists, navigators, referral services, and caregiver support services.</p> <p><b>1b.</b> Make templates of advance care directives and instructions publicly accessible through a central repository of materials.</p> <p><b>1c.</b> Collaborate with financial, legal, health, community, and advocacy organizations to increase awareness and utilization of advance planning opportunities.</p>
<p><b>2.</b> Increase the awareness of palliative care services in Hawai'i to help people with dementia and caregivers to have choice in where they receive care and the type of care.</p>	<p><b>2a.</b> Work with Kōkua Mau to develop campaigns incorporating education and awareness on palliative care and hospice care.</p>
<p><b>3.</b> Explore alternative strategies for long-term care financing.</p>	<p><b>3a.</b> Research and tailor policy to support strategies currently being implemented in other states/communities.</p>

## Kōkua Mau

**K**ōkua Mau is a statewide coalition that works to improve care for those who may be facing serious illness, their loved ones, and those who care for them. Begun in 1999, Kōkua Mau is Hawai'i's trusted resource for accurate information on Advance Care Planning (ACP), including Advance Directives and POLST, palliative care (which provides relief from the symptoms and stress of illness), and hospice care (which provides the best care possible at the end of life). Kōkua Mau means 'Continuous Care' in 'Ōlelo Hawai'i. Kōkua Mau's goal is that information and resources can be freely accessed so that the public and professionals are able to quickly and easily find the information they need, especially in times of distress and crisis. To maintain this access, Kōkua Mau has an actively managed website with free information and materials to download, an electronic newsletter with local and national events and resources, and provides ongoing training to professionals and public groups around the state. Kōkua Mau has a repository of Advance Care Planning documents in 11 languages, including Advance Directives and POLST. Kōkua Mau helps train professionals and community groups to start and conduct conversations to help people identify a healthcare agent, clarify what matters to them, and hopefully complete an Advance Directive. A variety of tools are on the website, including materials specifically for people with dementia and their caregivers. Kōkua Mau is the lead agency for POLST in Hawai'i and houses POLST information, forms, policies



and procedures, and other crucial information on our website. Begun in 2009, POLST is seen nationally as best practice for helping patients with serious illness (including dementia), and medical frailty have wishes and care plans be honored in an out-of-hospital setting. POLST is discussed with a patient and/or agent and signed by a healthcare professional (MD, APRN, PA) to be valid. POLST is honored by Emergency Medical Services (EMS) and is widely used around the state. Although it is a state mandate, Kōkua Mau receives no funds to run the POLST program. Although palliative care is an important type of care for those with serious illness, it is often misunderstood and underutilized. Kōkua Mau is working to develop materials and messaging to help providers, the public, and caregivers understand what palliative care is and the benefits it offers. Kōkua Mau is part of several national efforts to increase awareness and engagement on palliative care, including with Medicaid beneficiaries. For more information, visit [www.kokuamau.org](http://www.kokuamau.org).

## PUBLIC AWARENESS & EDUCATION

### I. Introduction

Hawai‘i’s unique cultural traditions and island environment would benefit from an innovative approach to raising public awareness and education by recognizing culturally relevant and culturally tailored approaches that value diversity, equity, and inclusion, especially in regard to traditionally unreached and underserved groups. As the number of people living with dementia in Hawai‘i continues to rise as the older adult population as a whole also increases, the need for continued public awareness and education about brain health is critical. Aligned with the CDC and Alzheimer’s Association’s Healthy Brain Initiative action item to “Educate and Empower,” that promotes cognitive health as a public health initiative, public awareness and education programs will strive to “increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers’ health and well-being.”

### II. Vision Statement

Develop culturally competent communication pathways that honor the diverse and unique communities of Hawai‘i to raise awareness about ADRD to the general public, especially caregivers and potential caregivers.

### III. Current Context

Since 2013, Hawai‘i has made substantial progress in improving public awareness about ADRD. The Alzheimer’s Association Hawai‘i’s ongoing mission is “to eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.” A commercial aired by the Alzheimer’s Association Hawai‘i from January to March 2019 resulted in a 72% increase in program contacts and a 57% increase in the number of physician referrals. Catholic Charities Hawai‘i also continues to offer in-person and online workshops on dementia care with speakers who address a variety of topics about dementia and caregiving. Dorothy Colby has held regular workshops and trainings throughout the year for multiple years on Teepa Snow’s Positive Approach to Care® program open to community members. A local chapter of Dementia Friends USA has existed in Hawai‘i since 2018. The University of Hawai‘i Center on Aging, the John A. Burns School of Medicine Geriatrics Workforce Enhancement Program, and St. Francis Healthcare System of Hawai‘i, as well as a number of non-profit organizations and faith-based organizations, periodically offer community workshops, classes, and presentations on dementia. Additionally, the Hawai‘i State Legislature appropriated \$1 million to EOA for an Alzheimer’s disease and related dementias public health campaign for FY July 1, 2023 to June 30, 2024.

## Being Present with “Nanay”: A Personal Story About Rosario Dulay

by Deanna Espinas

When my grandmother, Rosario Dulay, started exhibiting signs of dementia, we struggled to find accommodations. Our family could not afford to leave their careers to care for her. I weighed the option of perhaps working part-time to watch her myself. However, despite all our best intentions, we agreed to go forward with placement in a private adult residential home. I cried and felt so guilty when I left our grandmother at the home. It brought back memories of the first day of preschool for my own children. I remember how I parked my car after dropping them off. I cried quietly in the car by myself. I did the same that day. But it was the best decision. The caregiver sensed my hesitancy and reassured me that they would take good care of my grandmother. They said that I could visit and take her out whenever I could get away. I tried to visit as often as I could, and took her on outings usually by myself, and later with other family members and friends.

I want to thank friends and family who supported me when I brought Grandma to our gatherings. I thought she would enjoy not only my companionship, but seeing other people as well. People were all so kind taking turns sitting with my grandma, holding her hand as she repeated story after story, ending with, “What is your name? Are you my daughter?” Those moments gave me a chance to step away and take a break, to prepare a plate for her from the delicious potluck. But there were times when the commotion of loud voices and laughter became overwhelming for her. When well-meaning people rushed over to Grandma to engage her in lively conversation, someone would step in to help me by quickly intervening and explaining that Grandma and I just needed to be together, to sit quietly as we enjoyed our meal. I want to thank those special people and especially Grandma’s caregiver for allowing us to be part of this new community. I learned that I did not need to shout and raise my voice when I was with Grandma to “get her to remember things.” I needed to “chill” and be present with her in a loving way. It was hard. I was always looking for ways to get Grandma to remember: “Grandma, don’t you know who I am? Look at this picture of us!” She would have some moments when she remembered the past. But even when she couldn’t remember, I hope our smiles, gentle touches, and calming presence made her happy.



and explaining that Grandma and I just needed to be together, to sit quietly as we enjoyed our meal. I want to thank those special people and especially Grandma’s caregiver for allowing us to be part of this new community. I learned that I did not need to shout and raise my voice when I was with Grandma to “get her to remember things.” I needed to “chill” and be present with her in a loving way. It was hard. I was always looking for ways to get Grandma to remember: “Grandma, don’t you know who I am? Look at this picture of us!” She would have some moments when she remembered the past. But even when she couldn’t remember, I hope our smiles, gentle touches, and calming presence made her happy.

**Editor’s Note:** Deanna Espinas is one of an engaged group of caregivers or former caregivers in the community who have participated in developing and performing a play about the caregiving experience from the caregivers’ perspective. As part of the PlayBuilders of Hawai’i Theater Company, which has been creating plays with, for, and about the diverse communities in Hawai’i since 2011, “The Super Executive Aunties of the Mālama the Caregivers Collective” is scheduled to be performed during National Caregivers Month in November at a location and times to be determined. The play is based on stories of actual caregiving experiences collected during a series of “talk-story circles” and individual interviews organized and hosted by PlayBuilders. PlayBuilders understands that caregiving is part of the cycle of life and hopes that the theatrical exploration of the caregiving experience will “spark great conversations” that will benefit Hawai’i’s people. Look for publicity surrounding this event closer to the scheduled performance dates or check the PlayBuilders of Hawai’i website at [www.playbuilders.org](http://www.playbuilders.org) for updates. Resources on caregiving and dementia care will be available at the performance site.

## IV. Gaps & Challenges

Efforts to reach cultural and ethnic communities that are traditionally unreached or underserved or which experience a high burden of chronic disease should be pursued with culturally tailored content and approaches in mind, including outreach to neighboring island communities that do not have easy access to a wide variety of healthcare services. Additionally, research suggests that Alzheimer’s disease is likely to develop years, if not decades, prior to the appearance of signs and symptoms. If this is accurate, the need to reach people at an earlier age — youth and middle-age — with information about how to reduce the risk of developing Alzheimer’s disease later in life becomes even more compelling. This is especially important for communities that experience a heavy burden of chronic illness or engage in behaviors that put them at higher risk for Alzheimer’s disease later in life.

## V. Goals, Strategies, & Action Steps

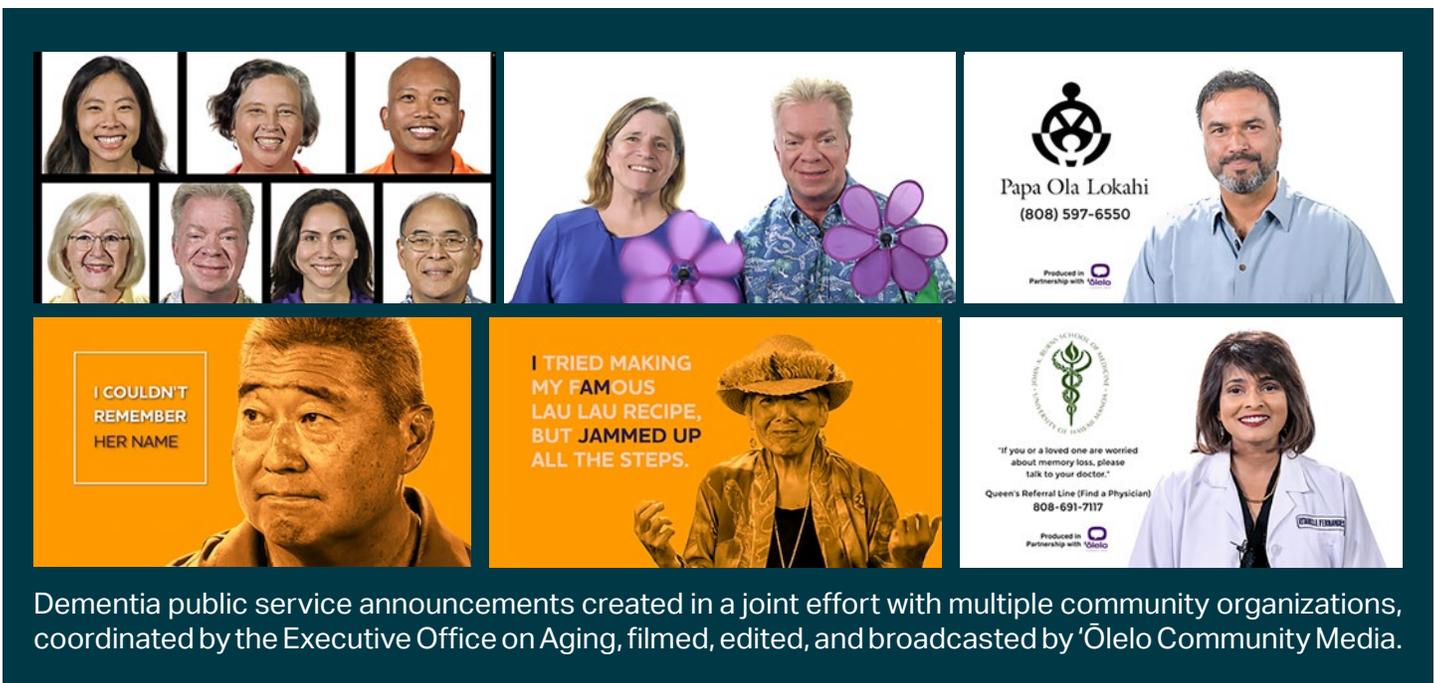
Partners in the coalition to raise public awareness and education about ADRD can work together to develop culturally competent communication pathways that honor the diverse and unique communities of Hawai‘i to raise awareness about ADRD to the general public, especially caregivers and potential caregivers. This can be accomplished through the following goals and strategies:

### GOAL I.

Partner with established community organizations and initiatives to develop cultural awareness and tailored strategies to engage target ethnic groups on matters of brain health and ADRD.

STRATEGIES	ACTIONS
<p><b>1.</b> Increase awareness of ADRD and resources through community outreach and engagement in ethnic communities statewide.</p>	<p><b>1a.</b> Carefully study the public awareness efforts to educate target ethnic groups in Hawai‘i about COVID-19 interventions and resources as exemplars of public awareness and education outreach.</p> <p><b>1b.</b> Offer information about access to ADRD assistance and resources in tandem with existing public health initiatives.</p> <p><b>1c.</b> Create language-inclusive resources for target distribution at culturally relevant events and gatherings.</p>
<p><b>2.</b> Network with cultural organizations, clubs, and associations in Hawai‘i.</p>	<p><b>2a.</b> Research if there is a directory of organizations, clubs, or associations; if not, create one.</p> <p><b>2b.</b> Contact leaders. Share CDC-BOLD Hawai‘i goals and objectives, and attempt to engage and encourage buy-in.</p>
<p><b>3.</b> Enlist popular and recognizable public figures from specific target groups to appear in public service announcements on dementia care.</p>	<p><b>3a.</b> Identify and reach out to potential public figures respected in target ethnic communities.</p>

STRATEGIES	ACTIONS
<p>4. Partner with community organizations that serve large numbers of target ethnic group members to provide their clients with educational “talk story sessions” about brain health and cognitive aging in alignment with the CDC’s Healthy Brain Initiative.</p>	<p>4a. Establish relationships and dialogue with organizations that serve large numbers of target ethnic populations.</p> <p>4b. Offer to set up education sessions for staff, volunteers, and clients who are interested in ADRD and caregiver support.</p>
<p>5. Create a directory of cultural organizations related to target ethnic groups.</p>	<p>5a. Identify cultural and religious organizations related to target ethnic groups.</p> <p>5b. Offer ADRD education and information assistance opportunities via those institutions.</p>
<p>6. Partner with existing healthcare research and outreach to target ethnic groups.</p>	<p>6a. Identify new and further build working relationships with potential partners who serve target ethnic groups.</p> <p>6b. Partner with organizations to provide sessions on ADRD with caregiver support education for staff and clients.</p> <p>6c. Seek out opportunities to utilize existing partner data collection methods to better understand ADRD in target ethnic groups in Hawai‘i.</p>



Dementia public service announcements created in a joint effort with multiple community organizations, coordinated by the Executive Office on Aging, filmed, edited, and broadcasted by 'Ōlelo Community Media.

## GOAL II.

Utilize conventional and creative channels to disseminate relevant ADRD messaging.

STRATEGIES	ACTIONS
<p><b>1.</b> Develop public service announcements or pay for ads that feature brain health and ADRD information on various media (i.e. print, broadcast, online, etc.) that attract target ethnic group audiences.</p>	<p><b>1a.</b> Identify appropriate ethnic media and other media outlets that will reach target communities.</p> <p><b>1b.</b> Collaboratively develop media materials and opportunities for brain health and ADRD public service campaigns.</p> <p><b>1c.</b> Request existing media kits and promotion information specifics from target ethnic group media outlets.</p> <p><b>1d.</b> Seek out opportunities to partner with sponsors and public health campaigns to create message synergy and alleviate promotional costs.</p>
<p><b>2.</b> In addition to enlisting churches to help with outreach goals, go to other locations where members of target ethnic groups congregate.</p>	<p><b>2a.</b> Identify churches with high target ethnic group attendance.</p> <p><b>2b.</b> Beyond the churches, identify restaurants, cultural groups, religious associations, and elsewhere that attract large target ethnic group participation.</p>
<p><b>3.</b> Enhance the visibility of brain health, ADRD, and caregiving at target ethnic group community events.</p>	<p><b>3a.</b> Identify appropriate cultural or religious events to engage target ethnic communities.</p> <p><b>3b.</b> Set up tables or booths with educational materials, resources, and language inclusive contact information.</p>

## GOAL III.

Develop culturally tailored ADRD messaging and resources for implementation in pilot public awareness campaigns.

STRATEGIES	ACTIONS
<p><b>1.</b> Start dementia care support groups geared specifically toward caregivers in the target ethnic group communities.</p>	<p><b>1a.</b> Partner with an organization that already offers caregiver support groups to offer culturally relevant caregiver support programs for target ethnic groups.</p>
<p><b>2.</b> Supplement existing online brain health, ADRD, and caregiving resources with materials in language inclusive formats.</p>	<p><b>2a.</b> Work with community partners to translate and update existing brain health and ADRD resources to accommodate the needs of target ethnic groups.</p> <p><b>2b.</b> Maintain and update content on webpage.</p>
<p><b>3.</b> Be aware of the variability of technology literacy in the target ethnic communities and propose means for addressing digital equity and accessibility in persons with dementia and their caregivers.</p>	<p><b>3a.</b> Train bilingual care navigators and Community Health Workers (CHW) to help clients navigate technology to locate resources.</p> <p><b>3b.</b> Promote outreach and digital literacy assistance training to high school and college students from target ethnic groups.</p>

STRATEGIES	ACTIONS
<p>4. Seek out and openly discuss innovative non-pharmaceutical and culturally tailored interventions and techniques with persons who are living with dementia but maintain some long-term memory capability or even “muscle memory.”</p>	<p>4a. Research latest available knowledge about best practices in non-pharmaceutical interventions, especially those that can be culturally tailored for target ethnic communities</p> <p>4b. Develop culturally tailored messaging on best practices that could be meaningful to target ethnic populations.</p>
<p>5. Gain an understanding of the historical differences between the various generations of specific ethnic communities in Hawai‘i.</p>	<p>5a. Talk to key cultural informants about the existing sensitivities and opportunities regarding the respective generational cultural identities, especially in terms of specific outreach to intergenerational communities.</p>

KITV4, KHON2, Hawai‘i News Now, The Kūpuna Network, Generations Magazine, and Honolulu Civil Beat are all using their platforms to raise awareness about issues that impact older adults and to share resources with the people of Hawai‘i.

#### GOAL IV.

Promote outreach and awareness on micro, mezzo, and macro levels (i.e., state, county, community, family, individual).

STRATEGIES	ACTIONS
<p>1. Keep policy influencers aware of efforts to raise public awareness about ADRD and dementia care to target ethnic groups in Hawai‘i.</p>	<p>1a. Communicate with Kupuna Caucus on relevant issues of brain health, ADRD, and dementia caregiving in target ethnic groups.</p> <p>1b. Identify and gain the support advocacy groups that engage with target ethnic communities on ADRD specific legislation.</p>
<p>2. Identify sources of financial assistance that can help pay for services and supports that assist caregivers and persons living with dementia.</p>	<p>2a. Investigate existing sources of financial assistance for target ethnic group caregivers along with available language assistance for target group languages.</p> <p>2b. Develop sustainable means for upkeeping financial support funding pipelines.</p>

## STRATEGIES

3. Engage care home associations in Hawai'i that represent community care home operators who run Adult Residential Care Homes or Community Care Foster Family Homes.
4. Contact local veteran organizations that serve members of target ethnic groups to offer brain health programs to veterans as well as their family members.

## ACTIONS

- 3a. Offer training and information to them about working with target ethnic group residents in their homes, sharing information about culture, language, norms, values, history, and so forth in an attempt to promote better cross-cultural communication and understanding.
- 3b. Offer ADRD workshops or seminars to organizations or associations of adult care home operators that include cultural competency considerations with the potential for qualifying continuing education credits.
- 4a. Identify veteran organizations in Hawai'i and promote opportunities to share brain health and ADRD information with veterans, as well as with their family members.



Lawmakers and advocates joined to raise awareness for Alzheimer's disease and related dementias on March 2, 2023. Photo Credit: Alzheimer's Association – Hawai'i

## GOAL V.

Engage the public in ways that raise intergenerational awareness of brain health, ADRD, and caregiving across the lifespan.

STRATEGIES	ACTIONS
1. Include the centrality of family in target ethnic groups when creating resources and messaging to members of these communities.	1a. Brainstorm on messaging concept and prototypes with key cultural informants, emphasizing the importance of family care and intergenerational relationships.
2. Engage bilingual students from target ethnic groups at the high school or college level who are interested in doing service projects or volunteer work in healthcare or geriatric care.	2a. Identify potential high school and college service-learning programs and health academies in communities with large target ethnic group populations. 2b. Work with ADRD service providers to create service learning opportunities. 2c. Integrate brain health and ADRD training into existing service learning curricula.
3. Provide an opportunity for language students to become friendly telephone visitors with target ethnic group older adults or caregivers to help keep them socially engaged and informed about available resources.	3a. Identify associated service learning opportunities.
4. Provide guidance and support for caregivers experiencing behavioral and communication challenges with persons with dementia.	4a. Seek out insights from cultural specialists regarding specific challenges that might affect intervention, such as reluctance to share private or personal burdens beyond household boundaries. 4b. Culturally tailor resources to help members of target ethnic groups address behavioral challenges.
5. Provide information to target ethnic group community members about the availability of respite care so that caregivers can get periods of rest and relief from their caregiving responsibilities.	5a. Investigate options for respite care that are culturally appropriate for target ethnic older adults.
6. Emphasize prevention and risk reduction topics for family caregivers as they may be more likely to get Alzheimer's disease if they are biologically related to a person living with the disease.	6a. Continue deep-dive research into modifiable risk factors for ADRD to stay abreast of latest research as well as research of chronic disease indicators for target ethnic groups on the Behavioral Risk Factor Surveillance Survey (BRFSS).

Teepa Snow teaches the Positive Approach to Care® for caregiving for people with dementia at the Ola Nā Lima Mālama: Hawai'i Caregivers Conference hosted by the Alzheimer's Association – Hawai'i at the Alohilani Resort Waikiki Beach on April 4, 2023. The conference was sponsored by Kahala Nui, Hale Kū'ike, The Queen's Health System, the City and County of Honolulu, Humana, and Arcadia. Photo credit: Alzheimer's Association – Hawai'i



**GOAL VI.**

Continue informed development of brain health and ADRD public awareness strategies.

STRATEGIES	ACTIONS
<p>1. Provide opportunities for stakeholders to submit feedback to inform future outreach and educational development.</p>	<p>1a. Work with partner organizations and service providers to offer satisfaction survey and comment card opportunities to clients and participants in brain health and ADRD programs.</p>
<p>2. Utilize lessons learned from pilot initiatives to expand awareness campaigns to other cultural communities reflective of Hawai'i's diverse populations.</p>	<p>2a. ADRD Coordinator to seek feedback from the Advisory Committee on meaningful ways to incorporate stakeholders feedback and program data to make existing efforts meaningful to a wider audience.</p>



## Working it Out Until the End: A Personal Story About Emi Hata

An interview with Akemi Simon, daughter

**D**ays before Emi Hata turned 102 years old in 2017, she was still working out at a Honolulu gym with her personal trainer Pat, just as they had been doing regularly for more than two decades. The workouts helped her to feel better and she persevered without complaint, said her caregiver and daughter Akemi Hata, who was interviewed for this story.

Born in a “little port town” in Hiroshima, Japan, in 1915, Emi was part of a large well-to-do family of six boys and six girls, with Emi being the youngest girl. She enjoyed a comfortable upbringing, and as a young woman married a man from a successful Hawai'i business family – the Hatas. As was the custom with some families of that era, the marriage was arranged by their respective families. The newly married Hatas maintained close ties with both Hawai'i and Japan due to the Hata family business, and both survived the bombing of Hiroshima where they happened to be living at the time toward the end of World War II. A U.S. citizen, Mr. Hata returned to Hawai'i and started his own business, and Emi followed once things stabilized. The Hatas had two children, Naomi and Akemi. Emi focused her energies on taking care of the home and her family while her husband built his business. Emi's husband died in 1974 when Akemi was in high school, and Emi, in accordance with her husband's wishes, made sure that both of her daughters were able to pursue their educational goals. Akemi went to Boston for school and completed an undergraduate degree in psychology and a master's degree in geriatric social work, a field in which she also worked for many years on the U.S. mainland and Hawai'i. Emi always told her daughters not to worry about her, but as she aged, she experienced more health complications, including debilitating pain from sciatica and arthritis. In 1988, like other adult children living outside of Hawai'i sometimes do, Akemi decided to return to the state to provide support for an aging parent.



In the early years after Akemi returned to Hawai'i, Emi tried to be independent and not impose too much on Akemi for help. But as Emi's care needs increased, Akemi gradually became more and more involved in Emi's day-to-day affairs. In 1993, Akemi married Gary Simon, who also worked in the healthcare industry and understood the demands of family caregiving. Gary and Akemi lived in a separate house on the same Mānoa property as Emi. Akemi helped establish a routine of care that Emi could live with on a day-to-day basis, and the arrangement also ensured that Emi would receive adequate nutrition and support while still maintaining a certain degree of autonomy in her own space. Things were going okay for a while, but Akemi noticed various signs that suggested her mother needed more assistance. Akemi eventually moved in with Emi. Akemi's sister, Naomi, would also help when visiting from California and provided a level of nurturing that balanced out the more managerial tasks of day-to-day caregiving. Naomi called Emi every night to check on her and talk story. The daily phone calls kept the mother and daughter connected and gave Emi something to look forward to at the end of the day. To support Emi as her cognitive health declined, Akemi began managing Emi's medications and taking over the cooking and some other tasks. Akemi began organizing more activities that were consistent with Emi's physical and cognitive abilities. Emi also attended adult day care at Furukawa Living Treasure and was a star pupil because of her proficiency in arts and crafts, although she

sometimes did not always remember making the crafts due to her memory problems. Akemi found various ways to keep Emi active and stimulated. She was able to coordinate outside help at times such as with transportation. Sometimes Akemi had to be more social worker than daughter—and vice versa—depending on the situation and circumstances. She learned through experience how to develop a constructive caregiving relationship with her mother. She engaged professionals to help convince her mother to do things that were beneficial to her well-being because her mother was sometimes more inclined to do what a doctor or therapist advised than what Akemi wanted her to do. Akemi learned to avoid arguing over differences of opinion or perspectives, opting for harmony over conflict whenever possible. She took the time to explain to her mother why they were doing the things they were doing. And she made sure to remember that even though her mother struggled with symptoms of dementia, she deserved to be treated with dignity.

In her early 80s, Emi suffered from what appeared to be a relatively sudden arthritic attack that emerged after coordinating a demanding social event. After consulting with medical specialists, it was advised that Emi begin regular physical therapy. She began water aerobics at the YWCA and physical therapy sessions, both of which really seemed to help. Akemi provided or arranged for the transportation. After doing this for six months to a year, Emi was able to stop her pain medications. Up to the end, Emi remained an important presence in her family's life. At one point, her college-age grandson decided to interview her for research about what life was like in Japan after the bombing of Hiroshima. To the family's surprise, she recalled more than they thought she would. It was not a topic she had discussed at length before. Emi passed away at home in her own bed at the age of 103 on January 17, 2019. Emi's grandson was set to return to school on the mainland the day after Emi died and the option was presented to postpone his return to school under the circumstances. Knowing how much Emi emphasized the importance of education, he decided to return to school to resume his studies. He felt that's what his grandmother would have wanted and expected him to do. Today, Akemi and Gary Simon continue to advocate for caregivers and persons living with dementia in honor of their beloved mother, Mrs. Emi Hata.

## WORKFORCE DEVELOPMENT

### I. Introduction

In tandem with promoting awareness of dementia in the public sphere, there is the need for a robust dementia-capable workforce that is prepared to meet the primary, secondary, and tertiary needs of persons living with dementia and their caregivers. Aligned with the CDC and Alzheimer's Association Healthy Brain Initiative action item to "Assure a Competent Workforce," efforts to "educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action" will be pursued.

### II. Vision Statement

To develop a workforce in Hawai'i with the capability and skills to deliver high-quality services and supports to the growing population with dementia and which can effectively address the complex and progressive impacts of dementia at all levels of society and recommend solutions.

### III. Current Context

Workforce development across the allied healthcare fields is a subject gaining greater traction in Hawai‘i as groups consisting of key stakeholders in the community are meeting to define the problems related to health-care recruitment, placement, and retention, and collectively brainstorm solutions. Not all of these efforts are focused specifically on developing a dementia-capable workforce, but as many of the clients who need long-term care and home care have cognitive impairment to some degree, it is anticipated that training and education should include supporting individuals with dementia, as well as their caregivers.

In 2019, the Geriatric Workforce Enhancement Program (GWEP) received funding from the Health Resources and Services Administration (HRSA) to focus on building geriatric workforce capacity while improving patient access to specialty healthcare in Hawai‘i’s rural communities. Training on dementia is a critical component of geriatric education and in creating age-friendly health systems. Finally, the Healthcare Association of Hawai‘i (with the American Health Care Association and the National Center for Assisted Living) is offering its members CARES® online dementia care training and the Alzheimer’s Association essentiALZ® certification program for individuals. This is the only online training option recognized by the Centers for Medicare & Medicaid Services (CMS). CARES® Dementia Basics & Advanced Care™ On-line Training Program is one of only three programs nationally recommended by CMS to meet its national nursing aide training requirements (part of Section 6121 of the Affordable Care Act mandates for enhanced nursing aide training).

### IV. Gaps & Challenges

The training and education of healthcare professionals are inconsistent when it comes to proficiencies in dementia care. Program developers would benefit from having convenient access to a wide range and variety of dementia resources aimed at students in the healthcare field, professionals already in practice, and non-professionals such as family caregivers in the community who are interested in the topic due to current or foreseeable caregiving responsibilities.

### V. Goals, Strategies, & Action Steps

#### GOAL I.

Pre-training: Develop ADRD resources and build career pathways and dementia capability modules into the training and education of aspiring health and human service workers.

STRATEGIES	ACTIONS
<p><b>1.</b> Develop, maintain, and publicize a master dementia-related curriculum to use as a comprehensive resource for educators and trainers in age-related subject areas.</p>	<p><b>1a.</b> Work with community partners in refining and structuring the drafted master curriculum to be inclusive of all dementia and brain health relevant materials at varying levels.</p> <p><b>1b.</b> House the master curriculum on an accessible web platform (e.g., on the EOA, or COA website).</p>

STRATEGIES	ACTIONS
<p>2. Engage in public messaging on recruitment and retention of a direct care workforce.</p>	<p>2a. Identify other groups working toward the development of a sufficient, dementia-capable direct care workforce.</p> <p>2b. Collaborate with community partners to provide professional development, good working conditions, and fair compensation in home and community-based services (HCBS) and long-term care (LTC) settings that service clients with dementia.</p>
<p>3. Explore, support, and advocate for intergenerational programs in Hawai'i that have the potential to make gerontology an attractive profession to young people.</p>	<p>3a. Identify best practices to inform the expansion of existing and creation of new intergenerational programs that help build positive relationships between young people and older adults.</p> <p>3b. Connect with and work to understand the needs of young caregivers of persons living with dementia through support organizations.</p>
<p>4. Promote the importance of brain health along with opportunities in the field of aging to young people.</p>	<p>4a. Identify high schools (e.g., those with health academies) and programs that support students with an interest in healthcare.</p> <p>4b. Outreach to target high schools and pilot presentations on brain health and the field of aging along with informing students about internships and service learning opportunities.</p>
<p>5. Consider alternative options to support the recruitment of a dementia-capable healthcare workforce.</p>	<p>5a. Explore government-supported public policy options that can facilitate recruitment of direct-care workers through transnational migration channels from outside Hawai'i.</p>



Dorothy Colby (above left) and Dr. Ritabelle Fernandez (right) facilitated dementia trainings for caregivers and professionals on Lāna'i in March 2023.

## GOAL II.

Ongoing training: Promote accessibility and utility of continuing education in AD/DR capability training for current health and human service professionals and para-professionals.

STRATEGIES	ACTIONS
1. Help to publicize continuing or enhanced educational and training opportunities in brain health and cognitive decline at all levels of professional development.	<p>1a. Work to infuse dementia content into the required curricula of pre-professional courses.</p> <p>1b. Develop capacity to provide credited continuing education in brain health for current professionals and para-professionals.</p> <p>1c. Provide accessible community education on brain health and cognitive decline for non-professionals, especially family caregivers, but also for the general public.</p>

## GOAL III.

Encourage the growth of dementia-friendly systems and dementia-informed communities.

STRATEGIES	ACTIONS
1. Maintain and update a directory of dementia-related specialists in Hawai'i.	1a. Gather and consolidate lists of geriatric and gerontological specialists, such as geri-psychiatrists, but have them all in one easily accessible location.
2. Strengthen collaborations among key age-related organizations.	2a. Expand upon current efforts to uncover and identify areas of common ground among other aging advocacy organizations.
3. Promote and participate in community engagement efforts and public service messaging in both traditional and social media, and explore other innovative pathways of public communication.	3a. Use all manner of communication (e.g., interpersonal, mass media, social media, etc.) to reach key stakeholders about workforce development concerns and priorities.



Dorothy Colby (above left) and Dr. Ritabelle Fernandes (right) facilitate dementia trainings for Moloka'i caregivers and direct care professionals funded by the Administration for Community Living Alzheimer's Disease Program Initiative Expansion Grant.

#### GOAL IV.

Organizational policy: Create supportive organizational environments.

STRATEGIES	ACTIONS
1. Identify, deliberate, and disseminate solutions for paying for dementia care services and supports.	<p><b>1a.</b> Identify and understand current sources of financing for long-term dementia care.</p> <p><b>1b.</b> Explore innovative solutions that are less known and have potential to relieve the cost burden for dementia care.</p> <p><b>1c.</b> Collaborate with partners to develop feasible policies to reduce the cost of dementia care.</p>
2. Learn about what other workforce development task forces or workgroups exist in Hawai‘i and share resources/work together where appropriate.	<p><b>2a.</b> Find common ground and opportunities to work collectively with the growing number of organizations focused on local and national workforce development issues toward solutions.</p>

#### GOAL V.

Public policy: Shape and advocate for public policy that helps to meet the needs of persons living with dementia and caregivers.

STRATEGIES	ACTIONS
1. Study and promote innovative models of worker compensation.	<p><b>1a.</b> Identify and understand existing models of worker compensation in home and community-based services (HCBS) and long-term care (LTC).</p> <p><b>1b.</b> Explore innovative compensation models that may be less utilized at present but have potential for attracting new talent to the dementia-capable workforce.</p>
2. Help publicize financial aid incentives, as well as explore the development of other financial aid incentives.	<p><b>2a.</b> Engage with the growing number of community and institutional programs that encourage students to enter healthcare professions.</p> <p><b>2b.</b> Work to infuse brain health and ADRD information into existing program materials.</p>
3. Monitor policy and legislation at the national, state, and local levels in healthcare and social policy related to workforce development.	<p><b>3a.</b> Keep an accessible record of current policy and initiatives relevant to workforce development in the dementia and long-term care sectors.</p>

## GOAL VI.

Break down and reframe the current stigmas related to cognitive decline to empower persons living with dementia and their support systems.

STRATEGIES	ACTIONS
1. Discuss an ethical decision-making framework for those who work with people living with dementia.	1a. Work with healthcare ethicists and cultural practitioners to begin a dialogue about caring for persons living with dementia, how to improve their quality of life through dignified and culturally appropriate treatment, and end-of-life and palliative care options.
2. Frame chronic illness and cognitive decline, including Alzheimer’s disease and related dementias, as a public health issue that impacts most, if not all healthcare specializations that treat chronic diseases.	2a. Promote the idea that ADRD is a public health concern that has implications at the micro, mezzo, and macro levels, and thus should be something society as a whole takes an interest in helping to resolve.

# SUSTAINABILITY

## I. Introduction

The older adult population is expected to continue exponential growth and the population of people living with ADRD is also expected to increase significantly. As this population grows, the need for statewide ADRD services and supports will exceed the capacity of the current aging network and health system. The implementation of the goals, strategies, and action steps detailed throughout this plan must be sustainable and scalable to meet this surging demand.

## II. Vision Statement

To sustain and grow ADRD services and supports statewide for many years to come.

## III. Current Context

In August 2023, EOA was awarded the CDC BOLD Public Health Programs to address the ADRD CDC-RFA-DP23-0010 grant to implement this state plan over a five year period. Additionally, the Hawai‘i State Legislature appropriated \$1 million to EOA for FY 2023-2024 to create a public health campaign on ADRD through HB 278, which was signed by Governor Josh Green on July 7, 2023 (Act 257, Gov. Msg. No. 1360). In 2023, EOA also filled the Alzheimer’s Disease and Related Dementia (ADRD) Services Coordinator position in the Executive Office on Aging “to coordinate the provision of public and private Alzheimer’s disease and related dementia services” pursuant to HRS 349-3.2.



## CATHOLIC CHARITIES HAWAII CIRCLE OF CARE FOR DEMENTIA



Catholic Charities Hawai'i (CCH) received an Alzheimer's Disease Programs Initiative (ADPI) grant from the Administration on Community Living (ACL) in 2018. The grant enabled CCH to establish the Hawai'i Circle of Care for Dementia Program to strengthen and expand the circle of care supporting persons living with memory loss and their caregivers by providing effective person- and family-centered dementia-capable programs, services, and resources to help them remain independent and safe in their communities.

Thousands of family caregivers and service providers benefited from caregiver trainings on a variety of topics ranging from brain health to managing dementia behaviors. Many of the trainings were recorded and are still available on the CCH website at [www.catholiccharitieshawaii.org/caring-for-persons-living-with-dementia-webinars-and-presentations](http://www.catholiccharitieshawaii.org/caring-for-persons-living-with-dementia-webinars-and-presentations). Education targeted for caregivers and service providers for persons with intellectual and developmental disabilities (I/DD) was also provided, including a video on I/DD and dementia.

An evidence-informed intervention called REACH (Resources for Enhancing Alzheimer's Caregivers' Health) Community was also implemented. Staff from CCH and other community organizations were trained as certified REACH Community coaches to provide this one-on-one program designed to inform and educate dementia caregivers about behavior management, mood management, and self-care. CCH also initiated two services specifically targeting persons living alone with dementia: case management and trained Memory Mentors volunteers.

CCH is grateful to receive Older Americans Act funding through the C&C of Honolulu Elderly Affairs Division, as well as generous private contributions, to continue many of the grant initiatives to support individuals with dementia and their caregivers. With another ADPI grant award from ACL in 2023, CCH will build dementia capability by: collaborating with The Queen's Medical Center Geriatrics Services for mutual referrals; implementing the evidence-based care-planning program SHARE for Dementia from Benjamin Rose Institute that engages adults to offer an Early-Stage Support Group; holding a Living Alone with Dementia Summit; and continuing to offer trainings for dementia caregivers and the I/DD community.

For more information, visit the CCH website at [www.catholiccharitieshawaii.org/hawaii-circle-of-care-for-dementia](http://www.catholiccharitieshawaii.org/hawaii-circle-of-care-for-dementia) or call the CCH Senior Services Intake Line at 808-527-4777.

## IV. Gaps & Challenges

The State of Hawai‘i currently does not have an ongoing budget dedicated to address ADRD in the coming years. EOA has grant funding to implement the ADRD State Strategic Plan until 2028 but nothing guaranteed or permanent beyond that. Generally, health insurance does not currently cover services for solely an ADRD diagnosis, except when services are related to other conditions.

For example, persons living with dementia who are ambulatory and able to physically complete activities of daily living (ADL), but unable to complete instrumental activities of daily living (IADL) independently due to cognitive impairment, and has limited financial resources, may not be able to access long-term care services through Med-QUEST or may have difficulty applying for and navigating public housing. However, if a person living with dementia needs assistance with ADLs, meets the qualifying level of care, and meets the financial criteria, then they may be eligible for long-term care coverage through Med-QUEST.

## V. Goals, Strategies, & Action Steps

### GOAL I.

Maintain and expand an engaged statewide coalition to improve implementation of the goals identified in the Hawaii 2035: State Strategic Plan for ADRD.

STRATEGIES	ACTIONS
<p><b>1.</b> Convene multi-sector coalition (e.g., advisory committee and workgroup members) and invite new individuals or organizations to get involved.</p>	<p><b>1a.</b> ADRD designated staff at EOA will meet with coalition members on a regular, feasible basis.</p> <p><b>1b.</b> Coalition will network with multi sector organizations and individuals who are interested in ADRD or whose work impacts people living with ADRD or overall community brain health.</p> <p><b>1c.</b> Empower coalition members to take ownership of implementing strategies and actions that they are interested in.</p>
<p><b>2.</b> Continue to build partnerships with stakeholders and collaborate on shared goals.</p>	<p><b>2a.</b> Support the initiatives of potential partners. Establish trust and build relationships with stakeholders. Identify shared interests with stakeholders. Collaborate on these efforts and ensure mutual benefit for continued participation.</p>

### GOAL II.

Pursue alternative funding sources for ADRD-related services and supports.

STRATEGIES	ACTIONS
<p><b>1.</b> Explore legislative policy changes that may appropriate funding to ADRD efforts.</p>	<p><b>1a.</b> Work with legal services, legislators, stakeholders, topic experts, and advocates on analyzing policies or drafting potential legislative proposals that improve systems, environments, and policies to support dementia.</p> <p><b>1b.</b> Participate in the legislative process through introducing bills, providing testimony, and advocating for ADRD efforts.</p>

STRATEGIES	ACTIONS
<p><b>2.</b> Research, apply for, and manage grants related to ADRD efforts.</p>	<p><b>2a.</b> ADRD-designated EOA staff will monitor new grant opportunities that may fund ADRD efforts.</p> <p><b>2b.</b> Collaborate with coalition members and contract with consultants as needed on applying for grants, managing grants, and grant reporting.</p>
<p><b>3.</b> Explore solutions for health coverage of dementia care.</p>	<p><b>3a.</b> Engage with Medicare, Med-QUEST, and other health plans to discuss options for coverage of dementia care (e.g. memory care, adult day care, companion care for supervision, etc.)</p>
<p><b>4.</b> Explore expanding health coverage to include palliative care and end of life care needs for PLWD.</p>	<p><b>4a.</b> Collaborate with community partners to explore working with health plans to include health coverage for palliative care and end of life care for PLWD.</p>
<p><b>5.</b> Seek ways to incorporate the goals, strategies, and actions of this plan into the existing workflow or structure of established funded programs.</p>	<p><b>5a.</b> ADRD-designated EOA staff will research existing supports and services.</p> <p><b>5b.</b> Engage and deliberate with stakeholders who can influence the existing workflow of established funded programs.</p> <p><b>5c.</b> Provide technical support to partners who incorporate goals, strategies, and actions into their organization’s workflow.</p>



# NATIVE HAWAIIAN ROAD MAP

In 2021, the CDC approved additional funds for EOA to develop a Road Map for Native Hawaiian brain health. EOA contracted these funds to Papa Ola Lōkahi (POL), a Native Hawaiian Health agency to develop the Native Hawaiian Road Map similar to the CDC’s Road Map for Indian Country. The complete Road Map – Navigating Impacts of Nā Ma’i Poina: Alzheimer’s Disease and Related Dementias Among Native Hawaiians<sup>4</sup> was prepared and produced by POL, and is available on the POL website at [www.papaolalokahi.org/program/kupuna-brain-health](http://www.papaolalokahi.org/program/kupuna-brain-health).

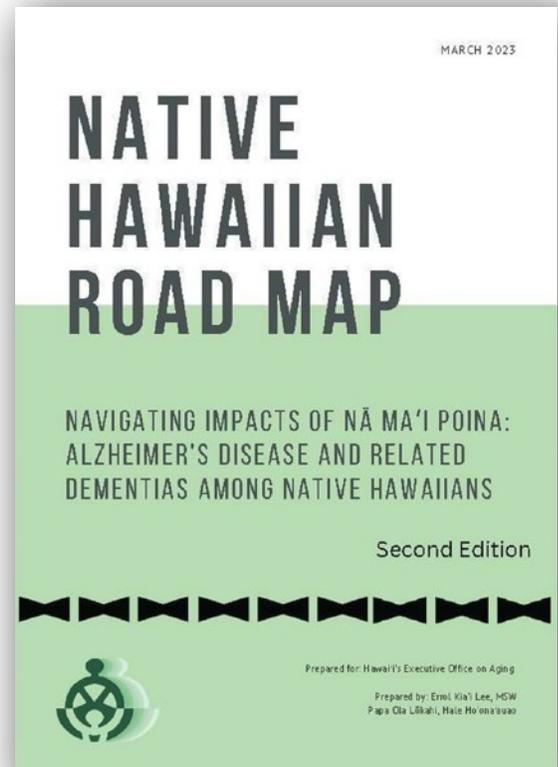
The following recommendations are primarily for, but not limited to, the EOA State Plan on Aging. It is inclusive of themes from statewide meetings, meetings with individual stakeholders, POL’s Community Healthcare Worker (CHW) network, and POL’s Traditional Healer’s Kūpuna Council. It also absorbs all the recommendations mentioned earlier in this document before the community engagement process began.

## RECOMMENDATION 1: DATA

- 1a.** Have a Native Hawaiian organization, such as POL, on the Hawai’i research consortium to expand research and programs to benefit Hawaiian families.
- 1b.** Align assessment and data gathering tools used among Native Hawaiian health organizations, state agencies (e.g., EOA), and universities (e.g., UH COA).
- 1c.** CHWs to assist with developing, implementing and collecting surveys in isolated rural Hawaiian communities.
- 1d.** Use disaggregated data to better understand Native Hawaiian health disparities and to ensure their health equity on a systemic level.
- 1e.** Improve collaborations and utilize a process to share data among stakeholders.
- 1f.** Support participatory and decolonizing approaches to research.
- 1g.** Grow more indigenous researchers who understand and respect Hawaiian culture.

## RECOMMENDATION 2: PROGRAMS & SERVICES

- 2a.** Define ADRD “testing” and “treatment” — locate ADRD specialists, educate families on how to access them, and understand assessment tools that they use.
- 2b.** Strengthen collaborations among stakeholder to increase early detection and regular screening for dementia; continue to work with service agencies and community members to identify and outreach to potential Hawaiian-serving partners.
- 2c.** Ensure informed and coordinated care and services for persons with dementia.



- i. Collaborate with Native Hawaiian doctors and the “Kauka Hui” to develop a list of ADRD specialists in Hawai‘i.
  - ii. Promote and implement navigational support utilizing an interdisciplinary, team-based approach to enable a smooth transition from hospital to home and follow-up care.
- 2d.** Add culturally-tailored brain health messaging to existing health promotion programs.
- 2e.** Promote and increase access to the Traditional Hawaiian Diet and other culturally relevant diet and nutrition resources.
- 2f.** Provide adequate and timely support for caregivers of persons with dementia.
- i. Identify opportunities to scale and sustain Recognize, Engage, Act, Call, Help is on its way (REACH) and Savvy Caregiver programs for Native Hawaiians.
  - ii. Provide comprehensive and culturally-tailored information and tools to help Hawaiians with dementia and their caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia, including wandering older adults.
  - iii. Promote and utilize support groups to receive advice, relieve stress, and share information and resources.
  - iv. Utilize volunteers to provide respite care and social support.
- 2g.** Better understand intergenerational caregiving relationships in local communities, and recognize potential caregiving barriers for youth caregivers and grandparents raising grandchildren.
- 2h.** Maintain the dignity and rights of people with dementia and their caregivers.
- i. Partner with the Native Hawaiian Bar Association and their elder law attorneys to offer presentations that cover dementia and legal issues including advance care planning, power of attorney, and trusts.
  - ii. Work with fiscal agents (e.g., OHA, Council for Native Hawaiian Advancement, Hawai‘i Community Foundation) to develop comprehensive financial planning for older adults and their families.
  - iii. Collaborate with Hawai‘i’s Adult Protection Services and utilize their recommendations to maintain a safe environment for older adults and caregivers.
  - iv. Enable Hawai‘i’s family caregivers and families to continue to provide care while maintaining their own health and well-being.
- 2i.** Ensure safety in medication management for older adults.
- 2j.** Partner with Hawaiian-serving organizations and programs to develop and promote culturally competent and tailored brain health practices.
- i. Integrate and implement indigenous and/or culturally relevant understandings of health and well-being into memory care programs and services.
  - ii. Utilize relationships with stakeholders and community partners to create and disseminate culturally-tailored approaches and implementation strategies.
- 2k.** Identify sources of financial assistance that can help pay for services and supports that assist caregivers and persons living with dementia.

- 2l. Improve digital literacy for home-bound older adults to access care and keep in touch with families.
- 2m. Develop long-term care and respite care homes on Department of Hawaiian Homeland properties.
- 2n. Increase housing and community-based services for aging Hawaiian elders.

### **RECOMMENDATION 3: POLICY**

- 3a. Increase collaborations to monitor policies and legislation at the national, state, and local levels in healthcare and social policies related to dementia and workforce development.
- 3b. Identify and understand current sources of financing for long-term care; explore innovative solutions to relieve the cost burden for dementia care.
- 3c. Advocate for a life-course practice model that fights discrimination and promotes equity in income, education, and opportunity, recognizing that healthy children have more opportunities to grow into healthy, long-living adults.
- 3d. Advocate for legislative support for making Long Term Service Support (LTSS) affordable and high quality, especially in underserved areas.
- 3e. Monitor policies to protect Social Security, Medicare, Medicaid, and Department of Health and Human Services (DHHS) programs that fund programs for Native Hawaiian elders.

### **RECOMMENDATION 4: PUBLIC AWARENESS & EDUCATION**

- 4a. Strengthen communication pathways to isolated rural Native Hawaiian communities to raise public awareness about ADRD.
- 4b. Utilize technology such as social media platforms and webinar capabilities to develop dementia-informed and dementia-friendly communities.
- 4c. Develop culturally-tailored resources on ADRD for Native Hawaiians.
- 4d. Develop literature on cognition, mental health, and spiritual beliefs and practices that focus on families and communities, not only on the individual.
- 4e. Increase access to resources that are culturally relevant, based on traditional practices, and offered in Hawai'i's official state language, 'Ōlelo Hawai'i.
- 4f. Educate Hawaiian families about ADRD to increase early detection and diagnosis.
  - i. Iterate that there is no cure for ADRD; prepare and equip families so they can live their best quality of life and allow their loved one to die with dignity.
- 4g. Increase access to training and education through community events, resource fairs, medical presentations, etc.
- 4h. Provide community-tailored education and services for the whole family about ADRD. Incorporate health and care for older adults in areas such as financial literacy, safety, transportation, and holistic lifestyle changes – healthy diet, minimize stress, consistent physical activity, and maintaining healthy relationships.
- 4i. Utilize community events and spaces to educate the public on brain health and promote advanced detection of cognitive impairment.

## RECOMMENDATION 5: WORKFORCE DEVELOPMENT

- 5a. Increase the healthcare workforce for older adults — train and deploy CHWs, social workers, nurses, and aides, especially to increase services to isolated and underserved rural communities such as West Kaua‘i (Kekaha) and Hāna, Maui.
- 5b. Increase trained caregivers by including youth; create a high school training pathway to encourage students to pursue CNA or CHW certificates.
- 5c. Publicize financial aid incentives such as Native Hawaiian Health Scholarships to grow the number of Hawaiian health professionals.
- 5d. Employ and retain gerontologists and other specialty doctors in Hawai‘i.
- 5e. Offer competitive salaries to reduce high turnover rates of health providers.
- 5f. Discuss an ethical decision-making framework that incorporates Hawaiian values, compassionate care, and cultural awareness for those who work with individuals with dementia and their families.
- 5g. CHW Training:
  - i. Teach how to assess a patient for dementia and what to do to refer them to appropriate care for diagnosis.
  - ii. Train and utilize CHWs for culturally-sensitive phone screenings to identify if a patient has dementia.
  - iii. Improve CHW training in dementia.
- 5h. Collaborate with the Hawai‘i State Health Insurance Program to educate and deploy navigators through their Kūpuna Navigator Program.

## CURRENT RESEARCH IN HAWAI‘I

### The Importance of a Research Registry

Despite the rapidly growing populations of Asian American, Native Hawaiian, and Pacific Islanders (AANHPI), less than 0.2% of the total NIH budget from 1992-2018 supported clinical research focused on AANHPI populations. Also staggering, less than 3% of participants in Alzheimer’s disease and related dementias (ADRD) studies in the National Alzheimer’s Coordinating Center database include AANHPI. The Collaborative Approach for AANHPI Research and Education (CARE) registry, under the leadership of the University of California San Francisco (UCSF), was launched in October 2020 to improve representation of AANHPI groups in ADRD, aging, and caregiving research. As of 2022, CARE has successfully enrolled more than 9,000 AANHPI participants in this research registry. The Center on Aging at the University of Hawai‘i is partnering with UCSF to engage diverse communities statewide in Hawai‘i and increase enrollment in the registry. Contact the UH Center on Aging to get involved at [uhcoa@hawaii.edu](mailto:uhcoa@hawaii.edu).



## NEAR Project Research on ADRD

**N**atives Engaged in Alzheimer's Research (NEAR) is a National Institute on Aging-funded project which seeks to expand treatment and research on Alzheimer's disease and dementia among indigenous populations, including Native Hawaiian, Pacific Islander, Native American, and Alaska Native communities. These are culturally and geographically diverse communities that have experienced health disparities, an unequal burden of conditions such as hypertension, type 2 diabetes, and low socioeconomic status that make dementia more likely. Led by Washington State University, the project will study how these conditions



can best be prevented, detected, and treated, and what role genetic risk factors play. "NEAR aims to address this gap in public health research by leveraging scientific resources across a network of community and academic partnerships," according to a John A. Burns School of Medicine press release. "This will be the first time that these Native populations have been included in this type of project grant from the NIA.

Topics rarely studied in Native and Pacific Islander populations will be investigated, including the use of culturally informed practices such as the

Hawaiian dance of hula to promote vascular health and prevent cognitive decline, and the role of sleep disorders in cognition." In addition to a number of research projects, NEAR is conducting brain health educational workshops that utilize visual and interactive learning methods. Activities include blood pressure monitoring, height and weight checks, grip strength tests, diet and physical activity reviews, cognitive battery surveys, and saliva collection with information about informed consent and genetic markers.

Collected samples are processed, stored, and cataloged at a repository at BYU with the aim to dramatically increase the number of specimens available for dementia research from underrepresented populations. To date, NEAR has conducted eight brain health workshops in Hawai'i. Members from the Native communities will be involved in the research, and culturally tailored interventions will be used. In Hawai'i, the practice of hula was previously found effective in improving blood pressure and reducing cardiovascular risk in Native Hawaiians. With the NEAR project, these kinds of culturally tailored interventions will be expanded to



include other diseases such as Alzheimer's. According to the JABSOM press release, "We are returning to the traditions of our ancestors to provide the solutions needed to address the most pressing health concerns of our communities today," said Joseph Keawe'aimoku Kaholokula, Ph.D., chair and professor of Native Hawaiian Health at JABSOM, as well as project lead for this Hawai'i-based project. Dr. John S.K. Kauwe, president of Brigham Young University-Hawai'i and professor of Biology at Brigham Young University in Provo, is involved as a project lead with NEAR and another project, Early Onset Alzheimer's Disease in Pacific Island Populations. This is a collaborative research project focused on establishing a Pacific Islander dementia cohort with the goal of contributing to the understanding of Alzheimer's disease progression by identifying and investigating genetic factors. Specifically, this project is developing and validating the first Alzheimer's disease diagnostic tools in the Samoan and Tongan languages.

## ‘IKE Kupuna Project

The goal of the ‘IKE Kupuna Project is to decrease the risk of Alzheimer’s disease and related dementia (ADRD) in Native Hawaiians and other Pacific Islanders. This population is more likely to have early-onset ADRD and associated vascular risk factors (e.g., hypertension and diabetes) than other ethnic groups. Native Hawaiians and other Pacific Islanders have been overlooked by large ADRD studies, and thus, very little is known about successful interventions in preventing cognitive decline in this population. Through our five-year National Institute of Aging-funded research effort, we will develop and test a culturally-grounded intervention based on the indigenous Hawaiian dance of hula utilizing a community-based participatory research approach. The ‘IKE Project builds on our prior research efforts that determined a six-month hula-based promotion program, *Ola Hou i ka Hula*, significantly improved blood pressure control in Native Hawaiians diagnosed with uncontrolled hypertension. The ‘IKE Project endeavors to replicate the success of the *Ola Hou* program, which has trained over 53 kumu hula and other cultural practitioners and has been implemented in over 18 sites across Hawai‘i. We have partnered with five community organizations in Hawai‘i to accomplish the following research aims. First, using group and individual interviews with cultural, scientific, and community experts to gather recommendations, we will modify the *Ola Hou* program into an eight-month program that leverages experimental learning for culturally relevant dietary education, cognitive exercises, and social engagement strategies. We will then conduct a group-randomized trial with Native Hawaiians and other Pacific Islanders aged 50–75 years with at least one modifiable vascular risk factor, such as hypertension, diabetes, or obesity, and subjective or mild cognitive impairment. We will recruit 16 cohorts of approximately 10 people each, with cohorts randomized for either immediate intervention receipt or a wait-list control condition. The primary outcome will evaluate change in vascular risk factors from baseline to follow-up at 6 and 12 months. The secondary outcome is change in cognitive function. We will also estimate the association between cognitive function and ApoE and TREM2 genotypes, as both are established genetic markers for ADRD in other populations. We will also conduct a rigorous health economics analysis to assess the cost-effectiveness and sustainability of the hula intervention in a community setting.



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*Submitted by Ke‘alohilani Worthington, MPH, ‘IKE Kupuna Research Coordinator, Department of Native Hawaiian Health, John A. Burns School of Medicine, University of Hawai‘i at Mānoa*

## Kuakini Medical Center Biomedical Research

**K**uakini Medical Center has gained local, national, and international recognition for its biomedical research. Since 1965, Kuakini has engaged in collaborative research efforts that have involved the National Institutes of Health (NIH) and its institutes, including the National Heart, Lung, and Blood Institute (NHLBI), National Institute of Aging (NIA), National Cancer Institute (NCI), and the National Institute of General Medical Sciences (NIGMS). Through its participation in scientifically sound and ethical research,

### Kuakini Medical Center

Kuakini has built an extensive track record of contributing to the NIH's mission of seeking fundamental knowledge and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. Kuakini has a rich research history in the areas of cardiovascular disease, brain aging (e.g., dementia, Parkinson's disease, and Alzheimer's disease), cancer, and clinical trials under cooperative group protocols.

Kuakini research programs and projects have produced over 700 scientific publications. These research findings have benefited the research participants and their families, enhanced the quality of Kuakini's health care services in promoting human health, strengthened Kuakini's research programs and its community service initiatives, and contributed to the NIH's mission. Kuakini's research programs have brought in over \$97 million in federal research funds and additional support of private research funds to Hawai'i since the 1960's.

### **Kuakini Honolulu Heart Program, Kuakini Honolulu-Asia Aging Study & Kuakini Honolulu Heart Program Offspring Study**

The Kuakini Honolulu Heart Program (Kuakini HHP), formerly funded by the National Heart, Lung, and Blood Institute since 1965, has been observing the incidence of coronary heart disease and stroke in about 8,000 men of Japanese ancestry living on the island of O'ahu. Results of the longitudinal study have played a part in the U.S. government's recommended dietary guidelines, in the development of "smoke-free" programs for primary and secondary schools, and in the development of rehabilitation programs for heart attack



Kuakini Honolulu Asia Aging Study

victims. The research findings, such as the existence of "good" cholesterol, have guided physicians worldwide in treating patients with heart disease. The Kuakini HHP is the only longitudinal study of Japanese-American men that has included epidemiological and clinical data of the cohorts for more than 50 years. From a worldwide perspective, it is one of few research programs that maintain a comprehensive, longitudinal database of demographic, lifestyle, and medical information on research participants as well as specimens collected from the participants.

An outgrowth of the Kuakini HHP is the Kuakini Honolulu-Asia Aging Study (Kuakini HAAS) that was established in 1991 and funded by the National Institute on Aging to study the Kuakini HHP research cohort regarding the causes of dementia, a disease that afflicts over 6.7 million Americans. The Kuakini HAAS continues to research the variables associated with brain aging, dementia, and Parkinsonism. Re-examinations of the Kuakini HHP participants has facilitated understanding of how genetic factors, diet, heart disease, various illnesses, occupations, and



Kuakini Honolulu Heart Program Offspring Study

other midlife experiences contribute to the development of disorders of the elderly. At the “Third World Congress on Vascular Factors in Alzheimer’s Disease” held in Kyoto, Japan, in April 2002, the Kuakini HAAS presented findings from the analyses of autopsied brain specimens donated by Kuakini HHP participants, who identified vascular and non-vascular pathogenic processes associated with poor cognitive function. In 2022, the published article on “Late-life social networks and incident Alzheimer’s disease: The Kuakini HAAS” presented the study findings on longitudinal associations between social networks and incidence of all-cause dementia, Alzheimer’s disease, and vascular dementia in 2,636 Kuakini HHP participants who were dementia-free at baseline, over a 10-year follow-up period. Those with strong social networks at baseline were less likely to develop all-cause de-

mentia. Therefore, prevention of social isolation of older adults should be considered a priority. Another outgrowth of the Kuakini HHP is the Kuakini Honolulu Heart Program Offspring Study, which is designed to collect data (including demographics, health conditions, lifestyle, and genetics) from the sons and daughters of the original Kuakini HHP participants. The goal of the study is to conduct multi-generational research on several diseases, health conditions, and healthy aging, including heart disease, stroke, high blood pressure, diabetes, age-related disability, memory loss, dementia, Alzheimer’s disease, Parkinson’s disease, cancer, longevity, and related genetic research. Kuakini believes that the linkage of the Kuakini HHP Offspring Study to the Kuakini HHP research will result in major scientific contributions that will benefit the Hawai‘i and global communities, as well as future generations.

## Hawaii Memory Disorders Center and Alzheimer’s Research Unit

**H**awaii Memory Disorders Center and Alzheimer’s Research Unit at Hawai‘i Pacific Neuroscience is 1 of 48 top neuroscience centers in the U.S. For over a decade now, our Hawai‘i memory & Alzheimer’s specialists and researchers worked tirelessly collaborating with other researchers around the world to develop innovative and novel treatments for this devastating neurological condition affecting more than 6 million Americans, including over 35,000 in Hawai‘i. Our mission is to provide options to patients who suffer from dementia, mild cognitive impairment, or preclinical state whose conditions are not satisfactory controlled on approved thera-



**HAWAII PACIFIC  
NEUROSCIENCE**

pies, or who are seeking advanced, innovative or research treatments. Our hope is that this will meet unmet needs of patients and their precious families in need of options and hope; Hawai‘i

physicians who want to incorporate research options as part of their comprehensive approach; local awareness; education on conditions; and empowering patients, families, and caretakers. Individuals with mild cognitive impairment or mild to moderate Alzheimer’s disease (AD) may be eligible to participate in one of the following studies: ATH-1017 LIFT (Synaptic Plasticity), Buntanetap (Axonal Transport), PRX012 (Next Generation Amyloid), Aducanumab ENVISION (Amyloid), GLP1-RA EVOKE (Glucose), or BIIB080 CELIA (Tau).

**LIFT-AD (Synaptic Plasticity).** Enhancing signaling between receptors in the brain has the potential to protect existing neurons from damage, reduce inflammation, promote regeneration, and positively modulate



Hawaii Pacific Neuroscience staff

brain activity. Results are being monitored not just with memory testing or CSF/PET biomarkers, but also by measuring brain network and connectivity using Quantitative EEG and P300 Event related potential.

**Buntanetap (Axonal Transport)** is administered via oral capsule. Its unique mechanism of action allows it to simultaneously inhibit multiple neurotoxic proteins which are at play in all neurodegenerative diseases. Buntanetap is the only drug so far to show improvement in cognition in AD patients and motor function in Parkinson's disease patients. Buntanetap has shown to reduce inflammation and preserve axonal integrity and synaptic functions, as well as neurotoxic proteins in previous Phase 2a studies. Buntanetap-treated AD patients showed a statistically significant cognitive improvement of 30% as measured by ADAS-Cog11 and in the WAIS Coding Scale when compared with baseline results.

**PRX012** is a next-generation, high binding potency antibody designed to enable subcutaneous dosing on a patient-friendly, convenient administration schedule, potentially providing greater accessibility for patients and caregivers. Preclinical data have shown that PRX012 binds to beta amyloid plaques and oligomers with high avidity, enabling effective levels of A $\beta$  plaque occupancy at relatively lower dose ranges. Additional pre-clinical data demonstrated clearance of both pyroglutamate modified and unmodified A $\beta$  plaque in brain tissue at concentrations of PRX012 estimated to be clinically achievable in the central nervous system with subcutaneous delivery.

**Aducanumab ENVISION (Amyloid)**. The accumulation of amyloid beta plaques in the brain is a defining pathophysiological feature of Alzheimer's disease. Clinical trials show the effect of ADUHELM on reducing amyloid beta plaques, a surrogate biomarker that is reasonably likely to predict clinical benefit, in this case a reduction in clinical decline. ADUHELM can cause serious side effects, including Amyloid Related Imaging Abnormalities (ARIA). ARIA is a common side effect that does not usually cause any symptoms but can be serious. Although most people do not have symptoms, some people may have symptoms such as: headache, confusion, dizziness, vision changes and nausea.

**GLP1-RA EVOKE (Glucose)**. Type 2 diabetes almost doubles the risk of developing AD and is associated with accelerated cognitive decline in people with mild cognitive impairment. Semaglutide has specifically been shown to reduce measures of neuro-inflammation which may affect cognition and function. In a post-hoc analysis of data from three large cardiovascular outcomes trials conducted by Novo Nordisk, the rate of developing dementia statistically significantly reduced by 53% in favor of GLP-1. Oral semaglutide (7 mg

and 14 mg) is approved as an adjunct to diet and exercise to improve glycemic control in adults with type 2 diabetes in the US, EU and Japan. This randomized double-blind placebo-controlled clinical trial investigates the effect and safety of Oral Semaglutide in Subjects With Early AD (EVOKE).

**BIIB080 CELIA (Tau)** is an antisense oligonucleotide (ASO) that may reduce production of the tau protein and its accumulation in brain cells, potentially slowing the progress of the disease. BIIB080 is an investigational antisense therapy designed to target microtubule-associated protein tau mRNA and prevent production of tau protein. This is a study to assess if BIIB080 can change clinical dementia rating-sum of boxes scores, and BIIB080 safety and tolerability when injected into the cerebrospinal fluid of participants with mild cognitive impairment due to AD or mild AD dementia between 50 to 80 Years of age (CELIA).

**Lecanemab (Leqembi)** is an intravenous antibody designed to remove amyloid deposits that have not yet clumped together. Leqembi should be initiated in patients with MCI (mild cognitive impairment) or in the mild dementia stage of AD. Leqembi demonstrated a statistically significant and clinically meaningful reduction of decline from baseline to 18 months on the primary endpoint, the Clinical Dementia Rating Scale Sum of Boxes

score, compared to placebo. People on the medication experienced side effects such as brain swelling and tiny bleeds common with similar amyloid-targeting drugs called ARIA. The study reported that 17% of people experienced small brain bleeds, compared to 8.7% in the placebo group. The side effects were detected in brain images but rarely caused symptoms. Since 2019, patients have been closely monitored for these side effects after receiving Leqembi at Hawai‘i’s first outpatient ambulatory Infusion Center by the experienced onsite infusion and neuroscience team.



Kore Liow, MD, FACP

“Our team of neurologists, neuroscience specialists, and researchers in Hawai‘i cannot be more proud of many of our Hawai‘i patients and their ‘ohana who have contributed to so many of these important Alzheimer’s research studies and many who continue to do so in the future, without which, we have no way of developing better options to those affected,” says Kore Liow, MD, FACP, Principal Investigator, Memory Disorders Center & Alzheimer’s Research Unit, Founder & CEO, Neurologist & Neuroscience Chair at Hawai‘i Pacific Neuroscience & Clinical Professor of Medicine (Neurology), Graduate Faculty, Clinical & Translational Medicine, University of Hawai‘i John A. Burns School of Medicine.

For more information, visit [hawaiineuroscience.com](http://hawaiineuroscience.com). Or call the Hawaii Alzheimer’s Research Unit Hotline at (808) 564-6141 or email [info@HawaiiNeuroscience.com](mailto:info@HawaiiNeuroscience.com).

## Rosalynn Carter, Former First Lady of the United States

Public figures and their families are increasingly coming forward to talk about dementia diagnoses in an attempt to help dispel the social stigma around openly discussing cognitive problems. In recent years we have heard about how dementia has impacted the lives of celebrities such as Tony Bennett, Glen Campbell, Jack Hanna, Robin Williams, Bruce Willis, and others. More recently, the family of Mrs. Rosalynn Carter, former First Lady of the United States, announced that she too is living with symptoms of dementia. A longtime advocate for caregivers and those in need of mental health care, Mrs. Carter, through her family, wanted to encourage members of the public to talk about dementia and caregiving with their families, friends, and healthcare providers.

On May 30, 2023, the family of Mrs. Carter released a public statement on the Rosalynn Carter Institute for Caregivers website announcing that she was living with symptoms of dementia. By sharing Mrs. Carter's diagnosis, her family wanted to reduce the stigma associated with this disease and encourage others facing similar circumstances to talk about the disease with their family members and healthcare providers. The full statement from the Carter family is re-printed below:

### Carter Family Statement about Health of First Lady Rosalynn Carter

The Carter family is sharing that former First Lady Rosalynn Carter has dementia. She continues to live happily at home with her husband, enjoying spring in Plains and visits with loved ones.

Mrs. Carter has been the nation's leading mental health advocate for much of her life. First in the Georgia Governor's Mansion, then in the White House, and later at The Carter Center, she urged improved access to care and decreased stigma about issues surrounding mental health. One in 10 older Americans have dementia, a condition that affects overall mental health. We recognize, as she did more than half a century ago, that stigma is often a barrier that keeps individuals and their families from seeking and getting much needed support. We hope sharing our family's news will increase important conversations at kitchen tables and in doctor's offices around the country.

As the founder of the Rosalynn Carter Institute for Caregivers, Mrs. Carter often noted that there are only four kinds of people in this world: those who have been caregivers; those who are currently caregivers, those who will be caregivers, and those who will need caregivers. The universality of caregiving is clear in our family, and we are experiencing the joy and the challenges of this journey. We do not expect to comment further and ask for understanding for our family and for everyone across the country serving in a caregiver role.



*Rosalynn Carter Institute for Caregivers (2023, May 30). "Carter Family Statement About Health of First Lady Rosalynn Carter." Retrieved from [rosalynncarter.org/carter-family-statement-about-health-of-first-lady-rosalynn-carter](https://rosalynncarter.org/carter-family-statement-about-health-of-first-lady-rosalynn-carter).*

## CONCLUSION

The Hawai'i Department of Health Executive Office on Aging (EOA) looks forward to implementing the goals, strategies, and actions developed in this Hawai'i 2035: State Strategic Plan on Alzheimer's Disease and Related Dementias (ADRD) to build a dementia care infrastructure and increase the state's capacity in collaboration with key stakeholders in the community representing a wide range of community-based organizations; government agencies; academic institutions; health systems and organizations; subject matter experts in public health and dementia; people living with dementia and their caregivers. In the coming years, EOA plans to continue to synthesize and coordinate efforts statewide using this State Strategic Plan as a blueprint in alignment with the CDC Healthy Brain Initiative Road Map. Consistent with the overarching goal to strive for diversity, equity, and inclusion in public health planning and programs, the road map for Native Hawaiian brain health and outreach to populations of heavy burden is a priority in fulfilling the mission of enhancing the quality of life for all of Hawai'i's people affected by Alzheimer's disease and related dementias.

This State Strategic Plan will support statewide efforts by our partners and stakeholders to achieve further gains in dementia risk reduction, early detection and diagnosis, caregiver support, and community-clinical linkages. This will involve strengthening partnerships and policies, engaging and educating the public, and building a diverse and skilled workforce, as well as using data to monitor health status and evaluate programs and services. This Healthy Brain Initiative Framework connects Hawai'i's State Strategic Plan to the larger dementia care infrastructure being developed nationally through the support and guidance of the Centers for Disease Control and Prevention (CDC).

Because a growing consensus of researchers believe that Alzheimer's disease develops in the human brain long before signs and symptoms appear later in life, the connection between chronic diseases, lifestyle choices, and brain health is a key public health takeaway message relevant to all age groups in the population. Maintaining a healthy weight, avoiding or effectively managing chronic diseases, staying healthy through physical activity, good nutrition, stress management, social support, continuing education, and regular healthcare monitoring are ways to lower the risk of cognitive decline. Different messages related to brain health, caregiving, and targeting the different levels of prevention that reflect cultural variations in views of health, disease diagnosis, and preferred help and treatments are needed. Additionally, a significant increase in persons living with dementia from various cultures in Hawai'i is anticipated. Representatives from groups working with AANHPI communities will be invited to participate on the advisory committee and workgroups to provide guidance in messaging to those population groups, although all those interested in participating are welcome. The Native Hawaiian Road Map also offers recommendations on providing dementia and brain health information to Native Hawaiians, especially in rural areas on O'ahu and the neighbor islands. EOA will support public awareness and education to promote healthy aging at all stages of life to improve healthy outcomes later in life.

As with the treatment of other progressive chronic and terminal illnesses, the treatment of people living with dementia is usually best provided by a multidisciplinary care team consisting of both informal and formal caregivers. When possible, the family is usually at the center of care, supported by professionals and paraprofessionals in the healthcare and social services fields, depending on what the particular needs of the person living with dementia are. As care needs increase and become more complex, the care team may expand to include more people, each contributing specialized knowledge and skills but working together to carry out an individualized care plan. In addition to healthcare and social support, persons living with dementia may also need financial and legal assistance, transportation alternatives, cultural and recreational enrichment, information and assistance, and guidance about long-term care and end-of-life options.

It should also be noted that the concept of family also includes individuals who play significant roles in each other's lives although they may not necessarily be biologically or legally related to one another. These "chosen" family members often play a critical role in groups where biological family relationships are either strained or non-existent. Also, family size has decreased over the decades and recent U.S. Census data have shown that a growing number of people on the younger end of the older adult age spectrum do not have biological children.

This will have implications for future caregiving options and requires planning and preparation by a cross-sector of key stakeholders in society to design and implement new — or reinforce existing — eldercare safety nets in coming years.

Caregiver support is central to the State Strategic Plan, as an estimated 60,000 unpaid family caregivers in Hawai'i are caring for a person with memory loss. If you're a caregiver for someone with dementia or have a family member or are a friend to someone with dementia, this plan provides information and resources that may be helpful to you. Please reach out to people and organizations listed in the resources section of this state plan if you need assistance. Remember that Alzheimer's disease and related dementias are brain diseases that may impair a person's memory, thinking, judgment, communication, personality and other abilities. The language and behaviors that they use to express themselves may be caused by the disease and should not be taken personally. In many cases, the person living with dementia is still able to feel emotions and appreciate reassurance and patience even when their ability to communicate decreases and appears confused and disoriented. Try to understand how their reality is changing and adjust to those changes in a way that is helpful and compassionate, rather than try to bring them back to a reality that their brains can no longer make sense of. Their favorite music from years back, reminiscence (or "talking story about the old days"), ability-appropriate recreational activities such as games and crafts, music, pet therapy, and spiritual enrichment are just some examples of stimulating interactions that may bring joy and comfort to a person living with dementia.

Although there is currently no cure for this devastating disease, we are encouraged by the strides that research is making to identify the causes of dementia and develop a possible cure. We will continue to support the important work that our own local researchers are doing to contribute to finding new treatments for a cure.

Everyone in Hawai'i deserves to live a life with the healthiest brain possible. This State Strategic Plan on Alzheimer's Disease and Related Dementias provides a number of pathways to expand this discussion across the state to include many voices from different sectors of the broader community. EOA and its coalition partners strive to lead with urgency and act for impact to achieve this goal through the implementation of this State Strategic Plan, building on our past successes, strengthening our present efforts and relationships, and moving forward by continuing to promote brain health and caregiving into our statewide public health practice.





# A Call to Action! We Need You.



This is a multifaceted issue that requires a multilevel and multi-sector response. Whether you're living with ADRD, you're a caregiver, a professional, an organization, or a community member, there are many ways to get involved and no experience is required. If you or someone you know is interested in helping to implement strategies discussed in this plan visit [www.hawaiiadrc.org](http://www.hawaiiadrc.org), or call EOA at (808) 586-0100. If you have a story to share, please contact us as well. Your story can inspire others. We need all hands on deck and would love to have you on board. Join the coalition today!



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<b>Blythe Nett</b>	Department of Health, Chronic Disease Prevention and Health Promotion Division
<b>Christy Nishita</b>	University of Hawai‘i, Center on Aging
<b>Sean Okamoto</b>	University of Hawai‘i, Telecommunications and Social Informatics Research Program
<b>Ray Rice</b>	Department of Human Services, Adult Protective Services
<b>Jodie Sanada</b>	Department of Health, Public Health Nursing Branch
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## Frequently Used Acronyms & Abbreviations

<b>AAA</b>	Area Agency on Aging
<b>AANHPI</b>	Asian American, Native Hawaiian, and Pacific Islander
<b>ACA</b>	Affordable Care Act
<b>AD</b>	Alzheimer's Disease
<b>ADL</b>	Activities of Daily Living
<b>ADRC</b>	Aging and Disability Resource Center
<b>ARD</b>	Alzheimer's Disease and Related Dementias
<b>ATRC</b>	Assistive Technology Resource Centers of Hawai'i
<b>BOLD</b>	Building Our Largest Dementia Infrastructure
<b>BRFSS</b>	Behavioral Risk Factor Surveillance Survey
<b>CDC</b>	Center for Disease Control and Prevention
<b>CIL</b>	Centers for Independent Living
<b>CMS</b>	Centers for Medicare and Medicaid Services
<b>COA</b>	Center on Aging
<b>CSHNB</b>	Children with Special Health Needs Branch
<b>DHHS</b>	United States Department of Health and Human Services
<b>DHS</b>	State of Hawai'i Department of Human Services
<b>DOE</b>	State of Hawai'i Department of Education
<b>DOH</b>	State of Hawai'i Department of Health
<b>DPS</b>	State of Hawai'i Department of Public Safety
<b>EOA</b>	Executive Office on Aging
<b>EOEL</b>	Executive Office on Early Learning
<b>HBI</b>	Healthy Brain Initiative
<b>HCBS</b>	Home and Community-Based Services
<b>IADL</b>	Instrumental Activities of Daily Living
<b>JABSOM</b>	John A. Burns School of Medicine, University of Hawai'i
<b>LTSS</b>	Long-Term Services and Supports
<b>MCI</b>	Mild Cognitive Impairment
<b>MQD</b>	MedQuest Division
<b>NIH</b>	National Institutes of Health
<b>OVS</b>	Office of Veterans' Services
<b>PABEA</b>	Policy Advisory Board for Elderly Affairs
<b>POLST</b>	Physician Orders for Life Sustaining Treatment
<b>REACH</b>	Resources for Enhancing Alzheimer's Caregiver Health
<b>SAMS</b>	Social Assistance Management System
<b>TASI</b>	Telecommunications and Social Informatics Research Program, University of Hawai'i
<b>VHA</b>	Veterans Health Administration

## Glossary

### Activities of Daily Living

Activities that individuals perform as a part of daily living: eating, dressing, bathing, toileting, transferring in and out of a bed or chair, and walking.<sup>28</sup>

### Aging and Disability Resource Center

An entity established by the State of Hawai'i as part of the state system of long-term care; serving as a highly visible and trusted source where people of all incomes and ages can obtain information on the full range of long-term support options; and as a single point of entry for access to public long-term support programs and benefits.<sup>28</sup>

### Alzheimer's Disease

An irreversible, progressive brain disorder and the most common cause of dementia. Early symptoms include difficulty with memory and thinking. As the disease progresses, symptoms include impaired communication and judgment, confusion, behavioral changes, and challenges with basic bodily functions. Symptoms usually progress over time, becoming severe enough to interfere with daily tasks. The brain changes of Alzheimer's disease include the accumulation of the abnormal proteins beta-amyloid and phosphorylated tau, as well as the degeneration of neurons.<sup>8</sup>

### Brain Health

A concept that involves making the most of the brain's capacity and helping to reduce some risks that occur with aging. Brain health refers to the ability to draw on the strengths of the brain to remember, learn, play, concentrate, and maintain a clear, active mind.<sup>2</sup>

### Caregiver

A spouse, adult child, other relative, partner, or friend who has a personal relationship with and provides a broad range of unpaid assistance for an older adult having a chronic or disabling condition.<sup>28</sup> (Used synonymously with "Care Partner")

### Chosen Family

A person's chosen family consists of people who play significant roles in each other's lives although they may not necessarily be biologically or legally related to one another. These "chosen family" members often play a critical role in groups where biological family relationships are either strained or non-existent.<sup>2</sup>

### Chronic Condition

Conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living, or both. Chronic diseases such as heart disease, cancer, and diabetes are the leading causes of death and disability in the United States.<sup>29</sup>

### Cognition

The mental functions involved in attention, thinking, understanding, learning, remembering, solving problems, and making decisions. Cognition is a fundamental aspect of an individual's ability to engage in activities, accomplish goals, and successfully negotiate the world. It can be viewed along a continuum — from optimal functioning to mild cognitive impairment to dementia.<sup>2</sup>

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## Community-Clinical Linkages

Connections between community and clinical sectors that aim to improve health within a community. They are an effective, evidence-based approach to preventing and managing chronic diseases such as Alzheimer's and other dementias.<sup>2</sup>

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## Creutzfeldt-Jakob Disease

A rare, rapidly worsening brain disorder that causes unique changes in brain tissue and affects muscle coordination, thinking, and memory.<sup>30</sup>

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## Dementia

An overall term for a particular group of symptoms. The characteristic symptoms of dementia are difficulties with memory, language, problem-solving, and other thinking skills. Dementia has several causes.<sup>8</sup>

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## Dementia Capability

Dementia capability means being skilled in identifying people with possible dementia, working effectively with individuals and caregivers, knowing what kinds of services are needed, and referring to agencies and individuals able to provide such services.<sup>31</sup>

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## Frontotemporal Dementia

The result of damage to neurons in the frontal and temporal lobes of the brain. Many possible symptoms can result, including unusual behaviors, emotional problems, trouble communicating, difficulty with work, or difficulty with walking.<sup>32</sup>

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## Gerontology

The multidisciplinary scientific study of the biological, psychological, and social aspects of aging that takes a broader view than geriatrics, which focuses more specifically on the healthcare needs of older adults.

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## Geriatrician

Doctors who have additional specialized training in treating older patients, especially those with multiple health problems or complex conditions.<sup>33</sup>

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## Geriatric Psychiatrist

A doctor that emphasizes "the biological and psychological aspects of normal aging, the psychiatric effect of acute and chronic physical illness, and the biological and psychosocial aspects of the pathology of primary psychiatric disturbances of older age. Geriatric psychiatrists focus on prevention, evaluation, diagnosis, and treatment of mental and emotional disorders in the elderly and improvement of psychiatric care for healthy and ill elderly patients.<sup>34</sup>

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## Health Equity

Achieved when every person has the opportunity to attain his or her full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances. Health inequities are reflected in differences in length of life; quality of life; rates of disease, disability, and death; severity of disease; and access to treatment.<sup>2</sup>

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## Huntington's Disease Dementia

A progressive brain disorder caused by a single defective gene that causes abnormal involuntary movements, severe decline in thinking and reasoning skills, and irritability, depression, and other mood changes.<sup>8</sup>

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## Instrumental Activities of Daily Living

Instrumental activities that individuals perform as a part of daily living preparing meals, shopping for personal items, medication management, managing money, using the telephone, performing light housework, performing heavy housework, and making use of available transportation.<sup>28</sup>

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## Lewy Body Disease

Dementia caused by Lewy bodies, "abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons...in a part of the brain called the cortex."<sup>8</sup>

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## LGBTQIA2S+

Lesbian, gay, bisexual, transgender, queer, (questioning), intersex, asexual, and (agender). Pasifika diversity language broadly describes these fluid concepts in the following terms: Māhū (Tahiti and Hawai'i), Vaka sa lewa (Fiji), Palopa (Papua New Guinea); Fa'afafine (Samoa and Tokelau), Akava'ine (Cook Islands); Fakaleiti (Tonga), Fakafifine (Niue).<sup>35</sup>

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## Mild Cognitive Impairment

A subtle but measurable decline in cognitive abilities that includes memory and thinking, but the ability to independently perform most activities of daily living are generally maintained. A person with mild cognitive impairment is at an increased risk of developing Alzheimer's or another dementia."<sup>2</sup>

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## Mixed Dementia

Dementia with brain changes associated with more than one cause. This is most common among people 85 years or older.<sup>8</sup>

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## Neurologist

A specialist who treats diseases of the brain and spinal cord, peripheral nerves, and muscles. This includes stroke, Parkinson's disease, uncontrolled headaches, memory loss, imbalance, numbness, pain, epilepsy, and multiple sclerosis, among many others.<sup>36</sup>

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## Neuropsychologist

A psychologist who specializes in understanding the relationship between the physical brain and behavior, and how the brain and systems relate to behavior and thinking. They look at what a person's brain does and how the person acts in life with regard to emotions, socially, physically, and more. They often work closely with other medical professionals.<sup>36</sup>

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## Neuropsychiatrist

A psychiatrist who works with people with mental disorders that are related to brain malfunction. They diagnose and treat disorders connected to the nervous system — the brain, spinal cord, or nerves. The specialty combines neurology and psychiatry.<sup>36</sup>

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## Neurosurgeon

A doctor who diagnoses and surgically treats problems with the central and peripheral nervous systems. The nervous system is connected to the brain and spine and other parts of the body, such as the arms, hands, feet, legs, and sensory organs.<sup>36</sup>

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## Parkinson's Disease Dementia

A brain disorder that causes unintended or uncontrollable movements, such as shaking, stiffness, and difficulty with balance and coordination, as well as changes in cognitive function, including problems with memory, attention, and the ability to plan and accomplish tasks.<sup>37</sup>

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### **Primary Care Physician**

A doctor who specializes in internal or family medicine. They facilitate regular check-ups and the coordination of care with specialists.<sup>38</sup>

### **Subjective Cognitive Decline**

An individual's perception that their memory and other thinking skills are worsening, independent of cognitive testing, a physician's diagnosis, or anyone else noticing.<sup>8</sup>

### **Traumatic Brain Injury**

An impact to the head that disrupts normal brain function.<sup>8</sup>

### **Vascular Dementia**

Changes to memory, thinking, and behavior resulting from... different conditions that interrupt the flow of blood and oxygen supply to the brain and damage blood vessels in the brain (e.g., strokes).<sup>39</sup>

### **Wernicke-Korsakoff Syndrome**

A memory disorder that results from vitamin B1 deficiency and is associated with alcoholism.<sup>40</sup>

## Appendices

*All Appendices can be accessed by visiting the website below:*

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

*Scroll to the bottom of the page and click on "Dementia Information."*

**Appendix A: Master Curriculum on ADRD**

**Appendix B: Memory Care Road Map for Family Caregivers**

**Appendix C: Native Hawaiian Road Map**

**Appendix D: Repository of Educational Materials**

**Appendix E: Statewide Inventory of Hawai'i Memory Care Organizations & Programs**

**Appendix F: Strategy Grids**

**Appendix G: Public Feedback**

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Hawai'i State Department of Health

Executive Office on Aging

250 S. Hotel Street, Suite 406

Honolulu, Hawai'i 96813

Phone: (808) 586-0100

Web: [health.hawaii.gov/ea](http://health.hawaii.gov/ea)