



**Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias:  
2020 Update**

\* Note: This report was made available for review and feedback through a 7-day public comment period (November 16-24, 2020).

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## Executive Summary

In compliance with Chapter §349-6.5 Hawaii Revised Statutes, the Hawaii Department of Health, Executive Office on Aging (EOA) is mandated to "prepare an update of the state plan on Alzheimer's disease and related dementias no less frequently than once per fiscal biennium". EOA contracted with the University of Hawaii, Center on Aging (COA) to facilitate and prepare this 2020 update of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias which was originally published in 2013 but has not been updated since then.

Due to the COVID-19 pandemic, the EOA and COA were largely restricted to virtual engagement of its Alzheimer's Disease and Related Dementias (ADRD) taskforce to complete this update (see Appendix A for a list of members). To encourage broad participation across the state, one method COA used was an online "Dementia Experiences Survey" (see Appendix B) during Summer 2020. The survey revealed these top three findings:

1. ADRD care partners need respite and more culturally appropriate long-term service and support (LTSS) options to sustain care of loved ones with dementia;
2. Hawaii needs more dementia-capable providers to identify and support residents living with dementia; and,
3. People living with dementia need more support to prepare for a pandemic, especially those who are living alone.

Despite the challenges shared by ADRD care partners and service providers, COA also heard many stories of reciprocity, hope, joy, and resilience. For example, one care partner shared during the 2020 Dementia Experiences Survey:

*"Although my mother-in-law lived for decades [with dementia] and my wife sacrificed her career and earnings and retirement benefits, we would take the journey all over again. The wisdom passed on from my mother-in-law to our extended family members is a legacy treasure. The keiki in our extended family developed a remarkable depth of compassion in being caregivers for years to one of their beloved kupuna." – from a care partner who lived with his mother-in-law with ADRD for more than 25 years (from 1994 to 2019)*

This report is an update of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias plan for the 2021 Legislature. In this report, the goals remained the same but updates are provided for: 1) activities since the plan was first published in 2013; and 2) strategies with input from the ADRD taskforce and larger community (through the Dementia Experiences Survey). This report was made available for review and feedback through a 7-day public comment period from November 16-24, 2020.

## **Introduction**

In 2018, the Hawaii State Legislature added Chapter §349-6.5, Hawaii Revised Statutes (HRS) requiring the Hawaii State Department of Health, Executive Office on Aging (EOA) to “prepare an update of the state plan on Alzheimer's disease and related dementias no less frequently than once per fiscal biennium. The EOA shall include information on progress made toward the goals of the state plan in its annual report to the legislature.” In EOA’s 2019 annual report, a status of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias was provided, see: <https://health.hawaii.gov/opppd/files/2019/12/EOA-Annual-Legislative-Report-2019.pdf>. In 2020, the ADRD task force and interested stakeholders convened to provide an update of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias which has not been updated since it was first published in 2013. Further necessitating this update, federal requirements and funding opportunities require states demonstrate and progress dementia capability, through person-centered, coordinated services for persons with ADRD and their care partners.

With this update demonstrating larger projections of Hawaii residents living with ADRD into the future than originally indicated, EOA has responded to the need to scale the capacity of Hawaii’s current health and LTSS systems. Since 2013, EOA and many ADRD community advocates have worked to demonstrate this burgeoning need while advocating for resources to support the growing demand. An ADRD Services Coordinator position was established in statute within the EOA (Chapter §349-3.2 HRS), and funding for the position was appropriated in EOA's budget but the position is in limbo due to a technical error that EOA will resolve in the 2021 Legislative session. While this position will undoubtedly propel implementation of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias, more support is needed. For example, there is no dementia-specific position within the Hawaii Department of Health, Chronic Disease Prevention and Health Promotion Division (CDPHPD), despite some efforts to demonstrate its need. The role of CDPHPD is to promote wellness and improve the quality and years of life for Hawaii’s people through effective prevention, detection and management of chronic diseases; recognizing dementia as a chronic disease is essential to developing systems to support dementia into the future.

## **Purpose and Methodology**

The purpose of this document is to update the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias, originally published in 2013. EOA contracted with COA to facilitate and prepare this update. The goals in the Hawaii 2025 State Plan are unchanged; COA solicited broad community feedback to update the state plan’s strategies. These strategy updates reflect Hawaii’s current ADRD landscape and future opportunities, and was gathered from the following three main sources:

- Feedback from the ADRD working group, which was reconvened for this update during three meetings (a kick-off meeting in March 2020, and additional virtual meetings in October 2020).
- An online “Dementia Experiences Survey” (Summer 2020) gathered statewide feedback from (n=141) ADRD care partners, service providers, and advocates.
- COA also sought additional feedback from key Hawaii’s ADRD community leaders, such as the Alzheimer’s Association- Aloha Chapter.

To guide the data updates, EOA and COA partnered with the Telecommunications and Social Informatics Research Program/Pacific Health Informatics and Data Center (TASI/PHIDC) group at the University of Hawaii. The TASI/ PHIDC group analyzed Hawaii-specific Medicare data for disease prevalence and healthcare services utilization, and health care costs accumulated over the course of ADRD. The growth of the state’s dementia population was forecast using Department of Business, Economic Development, and Tourism’s (DBEDT) Hawaii population models.

The following graphs and tables in the *Latest ADRD Data and Statistics* section include Medicare Fee for Service (FFS) beneficiaries from 2010-2014 in Hawaii who were aged 65 and older (younger persons comprised a small, non-representative sample and were not included) with at least 3 years of continuous coverage. In total, the sample included roughly 60,000 individuals without ADRD every year from 2010-2014, and approximately 9,000 individuals with ADRD every year (approximately 13%), for a total sample of 70,000 beneficiaries per year from 2010-2014.

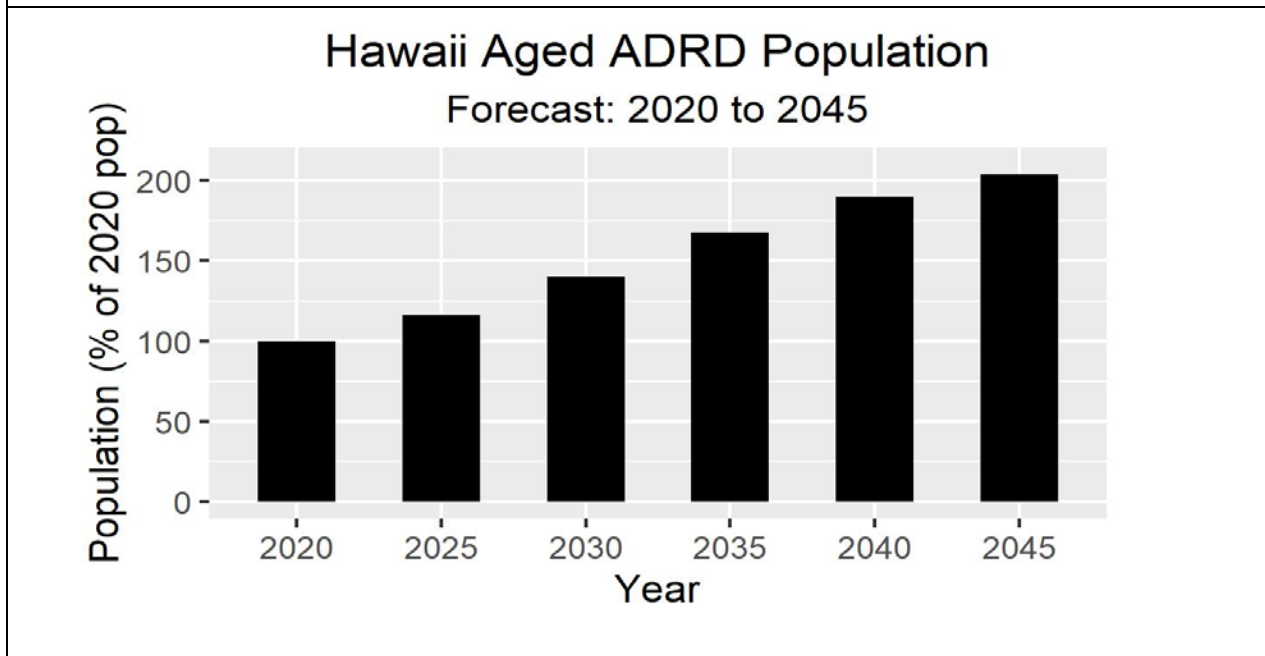
Limitations exist when working with this data set, however, and two items are noted. 1) ADRD rates by county or island are not possible due to privacy restrictions; and 2) limited data sets prevent reliability of ADRD rates by race/ethnicity, so disaggregated race rates are unavailable currently.

### **Latest ADRD Data and Statistics**

According to the Alzheimer’s Association’s 2020 Facts and Figures report, Hawaii is now home to approximately 29,000 individuals with Alzheimer’s disease, with an expected increase to 35,000 by 2025.<sup>1</sup> More than 66,000 care partners buffer that economic impact, acquiring 75,000,000 hours in unpaid care which quantifies to \$944,000,000 value in unpaid care.<sup>1</sup>

Table 1 indicates that the ADRD population in Hawaii will double between 2020 to 2045. The graph, based on Medicare FFS data and the DBEDT data, indicates that the growth in the ADRD population will reach 100% by 2045.

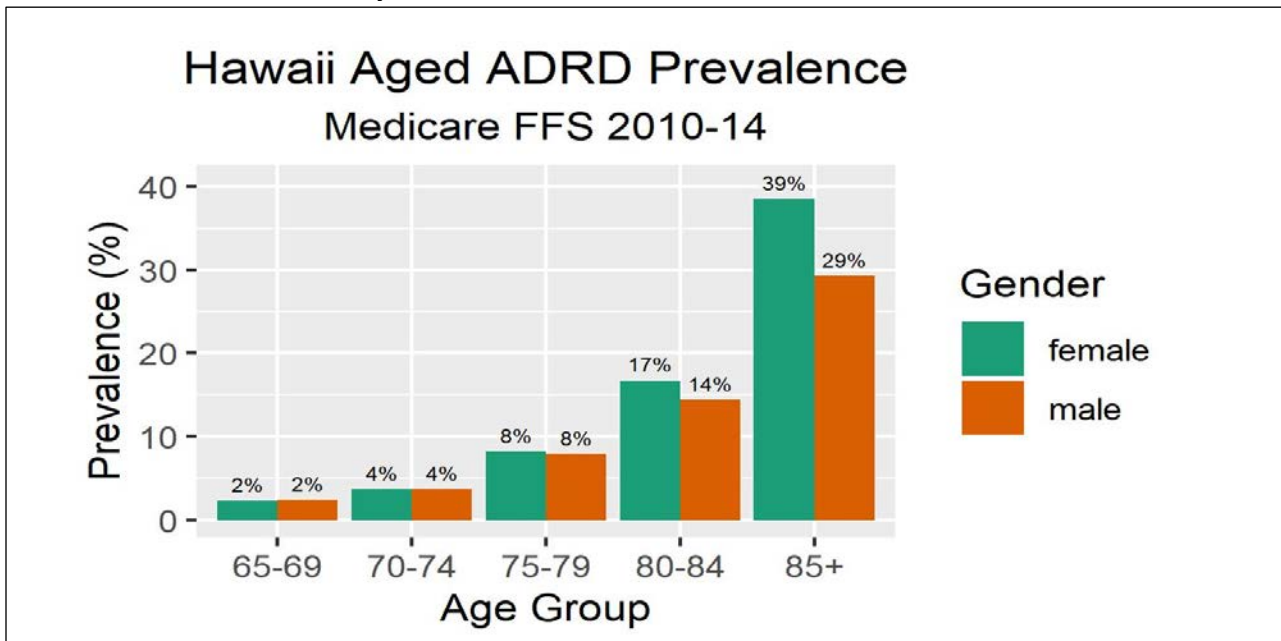
**Table 1: ADRD Population Growth**



Graph produced by UH TASI in Oct 2020

Table 2 indicates that ADRD prevalence is higher among females in Hawaii and this difference increases with age. Among the 85+ population, 39% of females and 29% of males have ADRD.

**Table 2. ADRD Prevalence by Gender**



Graph produced by UH TASI in Oct 2020

Table 3 shows that Medicare service utilization is substantially higher among the ADRD population. Using age-adjusted ratios, beneficiaries with ADRD utilized 8 times more hospice days, 7.5 times more skilled nursing facility days, and 4.3 times more acute inpatient days per year. Beneficiaries with ADRD also had 5.3 times more home health visits, 3.8 times more emergency room visits that became inpatient stays, 2.4 times more emergency room visits that became outpatient stays, and 2.2 times more outpatient hospital visits per year. The table also indicates that Medicare costs are higher per year among the ADRD population. In total, Medicare costs are nearly \$10,000 higher in the ADRD population in comparison to the non-ADRD population. The highest cost differences were in acute inpatient hospital costs (\$4,070), skilled nursing facility costs (\$2,198), and hospice care (\$1,206).

**Table 3. Medicare service utilization among ADRD and non-ADRD population**

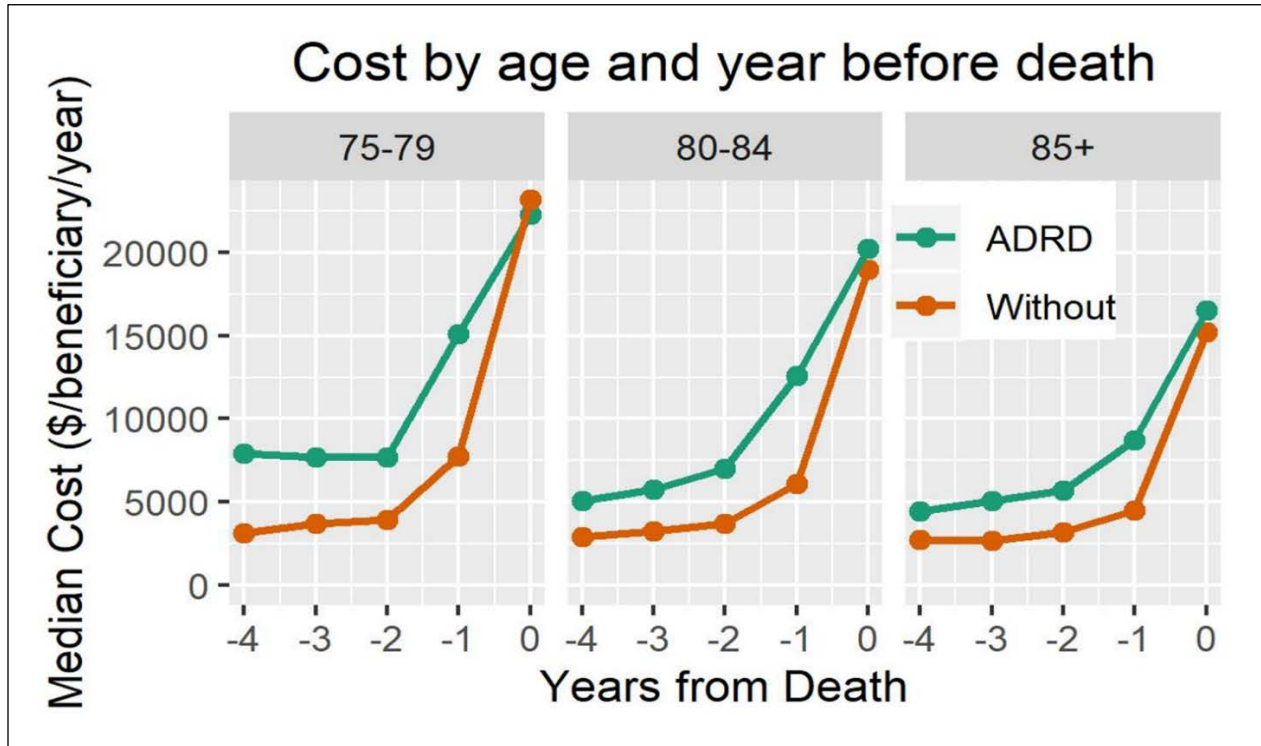
DAYS / Beneficiary / Year, average	Study Population			Age-adjusted	Metric
	ADRD	Without	Ratio	Ratio	
Hospice	7.6	0.6	13.1	8.0	Covered Days/bene/year
Skilled Nursing Facility	5.2	0.6	9.0	7.5	Covered Days/bene/year
Acute Inpatient Hospital	3.3	0.9	3.8	4.3	Covered Days/bene/year
Other Inpatient	0.3	0.1	4.2	5.0	Covered Days/bene/year
VISITS / Beneficiary / Year, average	ADRD	Without	Ratio	Ratio	Metric
Home Health	1.9	0.3	5.9	5.3	Visits / bene / year
Emergency Room -> Inpatient	0.4	0.1	3.8	3.8	ER Visits / bene / year
Emergency Room -> Outpatient	0.6	0.3	2.2	2.4	ER Visits / bene / year
Hospital Outpatient	8.1	4.8	1.7	2.2	Visits / bene / year

COST / Beneficiary / Year, average	Study Population			Metric
	ADRD	Without	Difference	
Total Medicare Payment	\$ 16,521	\$ 6,851	\$ 9,669	\$ / bene / year
Acute Inpatient Hospital	\$ 6,308	\$ 2,238	\$ 4,070	\$ / bene / year
Skilled Nursing Facility	\$ 2,487	\$ 289	\$ 2,198	\$ / bene / year
Hospice	\$ 1,307	\$ 102	\$ 1,206	\$ / bene / year
Drug, Part D	\$ 1,370	\$ 805	\$ 565	\$ / bene / year
Evaluation and Management	\$ 793	\$ 288	\$ 504	\$ / bene / year
Skilled Nursing Facility	\$ 432	\$ 42	\$ 390	\$ / bene / year
Home Health	\$ 455	\$ 77	\$ 378	\$ / bene / year
Hospital Outpatient	\$ 1,499	\$ 1,185	\$ 314	\$ / bene / year

Table produced by UH TASI in October 2020

Table 4 indicates that ADRD's costs accumulate over the course of the disease, with the highest costs incurred in the last year of life. ADRD sustains greater costs (ranging from \$2000 to \$4000) in the years prior to death with the gap closing in the last year of life.

**Table 4. Costs of ADRD in the years prior to death**



Graph produced by UH TASI in October 2020

From the lens of increasing prevalence of ADRD as well as high service utilization and high costs associated with the disease, the next section provides updates on ADRD state plan implementation activities since 2013 and revised strategies highlighting next steps toward creating statewide dementia capability.

### Recommendations

#### **Goal 1: Prevent and effectively treat Alzheimer’s Disease by 2025**

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

#### Progress in Hawaii Since 2013

Federal legislation has demonstrated a commitment to Alzheimer’s disease research and services. The enactment of the National Alzheimer’s Project Act (NAPA) propelled Congress to



increase Alzheimer's and dementia research funding more than six-fold, including two landmark allocations in 2019: 1) \$350 million for Alzheimer's and dementia research funding at NIH; and 2) \$10 million to implement the BOLD Infrastructure for Alzheimer's Act (P.L. 115-406). Both allocations acknowledge and intends to address Alzheimer's as a widespread public health crisis.

In pursuit of improved treatments and a cure, Hawaii has advanced clinical research in dementia. Hawaii's participation is vital to advancing research with Asian American and Pacific Islanders (AAPI), as the state and nation's AAPI communities are expected to grow into the future. One example was Hawaii Pacific Neuroscience's (HPN) establishment of Hawaii's first Genematch program. This genetic database registry is being implemented as part of the global Alzheimer's Prevention Initiative sponsored by [NIH/NIA Genematch Alzheimer's Prevention Registry](#). In addition, HPN's Alzheimer's Research Unit & Memory Disorders Center enabled an [HPN patient to become the 8<sup>th</sup> person in the world](#) to receive the first in human study to potentially prevent Alzheimer's using Anti-Tau Humanized Monoclonal Antibody IV Infusion.

#### ALZHEIMER'S DISEASE GENETIC TESTING IN HAWAII

Hawaii Pacific Neuroscience (HPN) provides E-cheek swab genetic testing for Alzheimer's ApoEgenes to all Hawaii residents 55-75 years old through the global API (Alzheimer's Prevention Initiative) network.

Research conducted by the John A. Burns School of Medicine, Department of Geriatric Medicine has examined dementia risk factors and since 2013 and has demonstrated that impaired renal function has been linked to cognitive impairment. The Honolulu Heart Program is a prospective study that began in 1965 with 8006 Japanese American men aged 45 to 68 years. The Honolulu Asia Aging Study began 20 years later, with cognitive assessment by the Cognitive Abilities Screening Instrument (CASI) administered to 3734 men. Findings indicated that mid-life proteinuria was an independent predictor for late-life dementia and cognitive decline over 8 years.<sup>2</sup>

#### Updated Strategies

1. Develop a Hawaii dementia research network that identifies and connects researchers conducting biomedical and social and behavioral research in dementia. The network will encourage and recruit diverse participants in research and support and translate evidence-based research into practice.
2. Convene a bi-annual dementia care and research symposium to foster scientific collaboration, share research findings, and set research priorities.

3. Build relationships with national organizations and mainland universities in order to conduct multi-site studies to increase federal funding opportunities and expand the impact of research findings.
4. Disseminate the latest research evidence to all stakeholders and the larger community through educational events, online sources, and the media.

#### NATIONAL RESOURCE

Collaborative Approach for Asian Americans and Pacific Islanders (AAPI) Research and Education (CARE) Registry:

- A national registry being developed to create a very large repository of AAPI research participants, with a focus on ADRD. These individuals can then be contacted in the future about research participation.
- The goal is to ensure adequate representation of AAPI in research studies.
- Registration in English, Cantonese, Mandarin, Korean, and Vietnamese
- <https://careregistry.ucsf.edu/about-care-registry>

### **Goal 2: Enhance care quality and efficiency**

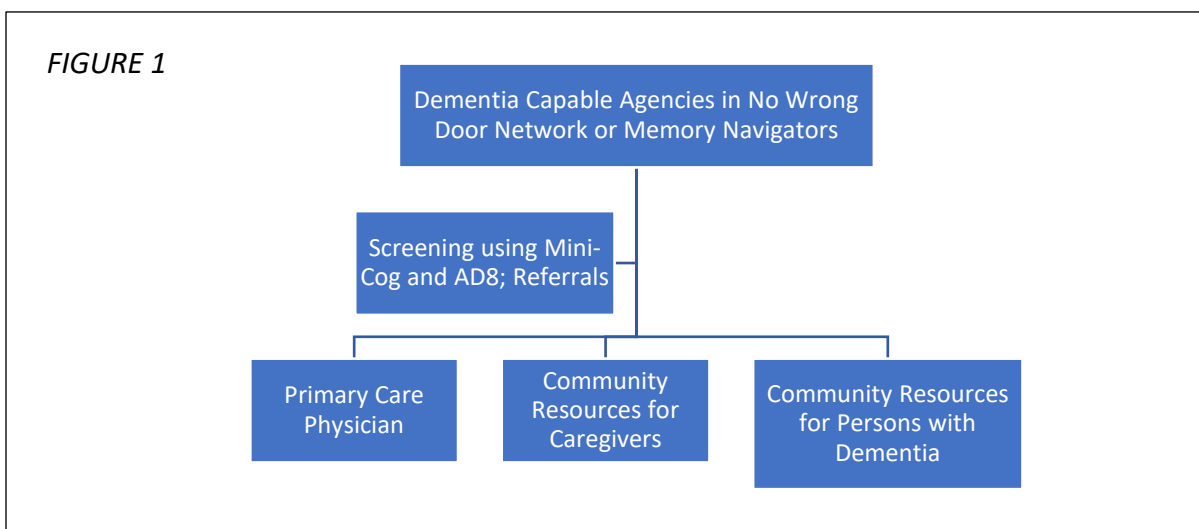
In order for Hawaii to achieve the vision of the best quality of life for those touched by dementia, it is imperative to achieve the highest quality of culturally competent care possible and a state infrastructure sensitive to the needs of people with ADRD and their care partners. Quality care begins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

#### Progress in Hawaii Since 2013

Statewide efforts have strengthened quality and efficiency of care and support for persons with ADRD. Hawaii’s statewide Aging and Disability Resource Center (ADRC) has a goal of streamlining and coordinating long-term services and supports (LTSS) for kupuna and persons with disabilities. The implementation of the ADRC was underway at the ADRD state plan’s original publication in 2013 and is now fully implemented by the four county Area Agencies on Aging (AAAs).

Beyond EOA and the county AAAs, EOA led a larger system change initiative to improve coordination of LTSS across state agencies. Through a cooperative agreement with Administration for Community Living (ACL) the EOA implemented a "No Wrong Door" (NWD) system. The NWD system provides a statewide coordinated system of information and streamlined access for all persons needing LTSS. For dementia LTSS, individuals and care

partners can access support through any “Door” at one of the following agencies: the four county AAAs operating the ADRC, Med-QUEST Division (MQD, the state Medicaid agency), Developmental Disabilities Division (DDD), Children with Special Health Needs Branch (CSHNB), Division of Vocational Rehabilitation (DVR), Office of Veterans' Services (OVS), Veterans Health Administration (VHA), Centers for Independent Living (CIL), Adult Mental Health Division (AMHD), Office of the Governor's Coordinator on Homelessness (GOVH), Adult Protective Services (APS), and Assistive Technology Resource Center (ATRC). Staff at these agencies have been trained to do memory screenings (i.e., Mini-Cog and AD8) and have adopted dementia-capable protocols to refer families to their primary care physician for further cognitive assessment and dementia capable providers of LTSS in their community (see Figure 1).



Other community initiatives have also expanded care quality and efficiency. In 2018, The Queen’s Medical Center-Punchbowl was the first hospital in Hawaii (fifth in the nation) to be accredited as providing the highest level of care to the geriatric population as a Level 1 Geriatric Emergency Department by the American College of Emergency Physicians (ACEP) while the Queen’s Medical Center-West Oahu received a Level 2 designation and both Molokai General Hospital and North Hawaii Community Hospital received Level 3 accreditations.

In addition, there is a growing recognition of the need to grow Hawaii’s dementia capable workforce, evidenced by the John A. Burns School of Medicine’s (JABSOM) Geriatric Workforce Enhancement Program (GWEP). GWEP received additional funding in 2019 from the Health Resources and Services Administration (HRSA) to focus on building geriatric workforce capacity while improving patient access to specialty health care in Hawaii’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 Hawaii (with American Health Care Association and National Center for Assisted Living) is offering members CARES® online dementia care training

and the Alzheimer's Association essentialALZ® certification program for individuals. This is the only online training option recognized by CMS. CARES® Dementia Basics & Advanced Care™ Online Training Program is one of only three programs nationally recommended by the Centers for Medicare & Medicaid Services (CMS) to meet its national nursing aide training requirements (part of Section 6121 of the Affordable Care Act mandates for enhanced nursing aide training). The CARES Program™ is an online dementia care training program.

Updated Strategies:

1. Launch initiatives in partnership with primary care providers to promote best practices in brain health and chronic disease management across the lifespan.
2. Build a health care workforce, including professionals, paraprofessionals, and allied health care partners with the skills to provide high quality care for people with ADRD.
3. Identify and provide ongoing dementia training on topics that will support quality care to care home operators, long-term care providers health care providers including, but not limited to nurse practitioners, EMS and other first responders, providers in homeless shelters, and care coordinators at health plans.
4. Discuss standardizing and mandating dementia training for first responders and city and county transportation providers, including bus drivers and HandiVan drivers.
5. Align with existing educational efforts to avoid duplication. For example, the Geriatric Workforce Enhancement Project (GWEP) is currently working on expanding Project ECHO (Extension for Community Healthcare Outcomes) to long-term care settings.
6. Incentivize, foster, and develop Hawaii's geriatric workforce by reaching students at earlier stages.
  - 6a. Modify high school curriculums to include mandatory or elective health-related and aging courses.
  - 6b. Integrate dementia education within higher education including, but not limited to medical, nursing, social work, pharmacy, and public health programs. Curriculum to include dementia capability, care navigation, and interdisciplinary care coordination.
7. Implement policy changes that require dementia education for provider continuing education and recertification. Allow for multiple methods of delivery including virtual and self-directed training.
8. Ensure timely and accurate diagnosis by training all primary care physicians and nurse practitioners in memory and dementia screening and access to referral resources.

9. Train on best practice and evidence-based screening tools available- i.e., Mini-Cog, AD8, National Task Group for Intellectual Disabilities and Dementia Practices screen tool for intellectual and developmental disabilities population. Ensure cultural sensitivity of screening tools for Native Hawaiian/Pacific Islanders.
10. Identify high-quality dementia care guidelines and measures across care settings
  - 10a. Select the best existing and evolving dementia care guidelines and measures being used locally and nationally to adapt to the spectrum of Hawaii service providers and care settings, including primary care physicians, the direct care workforce, Hawaii's aging and public health workforce, and care partners.
  - 10b. Examine cost-savings models of dementia care and explore feasibility for application in Hawaii's care settings.
11. Ensure that people with ADRD experience coordinated care and transitions between health care settings and between acute and long-term care systems.
  - 11a. Examine evidence-based care transitions models to reduce unnecessary hospital readmissions and emergency room use by people with ADRD.
  - 11b. Explore options for care planning/coordination across a range of medical professionals, insurance companies, and hospital systems. These options should support better outcomes for all and can be scaled into the future.
12. Build capacity to address an increasing number of behavioral crises that occur in patients with dementia. Create a special workgroup to find ways to identify barriers, enhance training, and expand capacity of geriatric psychiatric and crisis services statewide.
13. Standardize electronic medical records across care settings to streamline referrals and ensure efficient system tracking after diagnosis to include follow up, data collection, and continuous monitoring.
14. Streamline and standardize ADRD discharge information from acute care settings. Discharge packets to include resources on dementia capable providers, legal planning (including pro bono resources for ADRD families, completion of guardianship and capacity assessment, advance care planning), caregiver support, and respite programs.

15. Advance and expand coordinated and integrated health and long-term services and supports for individuals living with ADRD by expanding interdisciplinary models, similar to the memory clinic model at Kokua Kalihi Valley, to different settings.
16. Improve quality of care for populations in Hawaii who are disproportionately affected by ADRD, including but not limited to individuals with: Down Syndrome and traumatic brain injury, as well as improve access to care for those with early onset dementia, homeless and those living in poverty with dementia, residents of rural areas with limited access to providers and specialists, and those from different ethnic groups, with a particular focus on Native Hawaiians and Compacts of Free Association (COFA) residents.

#### LOCAL RESOURCE

The evidence-based Geriatric Resources for Assessment and Care of Elders (GRACE) model of primary care is available through Aloha Care, offering home-based geriatric assessment and care management as part of an interdisciplinary team for individuals who have geriatric conditions, including ADRD.

### **Goal 3: Expand supports for people with Alzheimer’s disease and their families**

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

#### Progress in Hawaii Since 2013

The longstanding leadership of the Alzheimer's Association in Hawaii’s communities continues, with the Aloha Chapter expanding their supports for people with Alzheimer’s disease and their families by developing a new caregiver support group on Molokai, with the hope of providing more dementia related supports. Through a partnership with the Hawaii County ADRC, The Aloha Chapter also developed a Memory Café Hui at the Hilo ADRC, which has pivoted to a virtual cafe in 2020 due to the COVID-19 pandemic.

Resources restricted EOA’s execution of the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias, but a series of grants awarded to Hawaii by the federal Administration for Community Living (ACL) provided critical resources for implementation. In 2015, the University of Hawaii Center on Aging (COA) was awarded a dementia grant from ACL to create the Hawaii 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 practice, that was implemented by the Public Health Nurses and Project Dana volunteers. The memory care navigator model promotes early screening and identification, education, and connection to community resources. The federal grant also implemented the evidence-based Savvy Caregiver program in Hawaii, a psychosocial program designed to improve the practical skills of dementia caregivers. Hawaii'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, meaning that they 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- Aloha Chapter. Funding also enabled the continuation and expansion of Savvy Caregiver program to other parts of the state. This funding also 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 C).

In 2019, Catholic Charities Hawaii (CCH) received federal funding from the ACL to create the Hawaii Circle of Care for Dementia. One grant objective is to implement the evidence-based REACH program, an educational program to improve 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 intellectual and developmental disabilities (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).

These 3 federal grants have enabled Hawaii to pilot and evaluate evidence-based and best practice programs and approaches. Training provided to health care professionals and family caregivers address critical needs, particularly in the areas of awareness and knowledge of ADRD.

Lastly, in 2019, Senator Brian Schatz cosponsored the [Younger-Onset Alzheimer's Disease Act of 2019](#) (H.R. 1903/S. 901) to create supports for people living with ADRD who are under the age of 60 years and do not have access to services from programs provided by the Older Americans Act, including nutritional programs, respite services for family caregivers, supportive

services, the National Family Caregiver Support Program, and other services that enhance quality of life. ADRD is not just a disease of old age, younger onset dementia is devastating because the individual is diagnosed in their 30s, 40s, and even 50s. State policy changes are likely needed to effectively support those with younger onset dementia.

### Updated Strategies

1. Ensure that Hawaii care partners and families receive culturally sensitive education, training and support materials.
  - 1a. Culturally sensitive materials and trainings will be identified and expanded, then distributed throughout the community. This should include health information technology found through online links and referrals, available not only from home computers but in community settings.
2. Examine the COVID-19 pandemic's impact on how community-based, services and supports are provided. A dementia care provider shared in the 2020 Dementia Experiences Survey:  
*"The senior center I am the head of has closed, so we have had to offer online classes to seniors. However, many of them do not have computers or smart phones to access such programming. We are making phone calls to every senior center member and mailing birthday cards to keep their spirits high and to assist them to fulfill their basic needs and connect them with community services. It is a time that the human spirit shines brightly with the kindness, appreciation, and thoughtfulness shown by seniors and their families, the community and our staff."*
3. Empower Hawaii's family caregivers and families to continue to provide care while maintaining their own health and well-being.
  - 3a. Utilize peer mentors or coaches, more access to care partner support groups, affordable transportation options especially in rural areas, and available and affordable respite services inside and outside the home.
  - 3b. Collaborate with employers and the business community to offer flexible employee benefits and policies to employees who are balancing work and caregiving.
4. Assist individuals and families in planning for future care, legal, and financial needs, while considering the cost and impact of dementia.
  - 4a. Hold annual summits that will feature national presenters on all the options for LTSS: private, public, and innovative, like participant-directed services programs.
  - 4b. Create a resource list of financial professionals, organizations, and providers that can offer pro bono or affordable services for families impacted by ADRD.



- 4c. Develop resources for capacity assessments and guardianship support for persons with ADRD, especially during the COVID-19 pandemic.
5. Maintain the dignity, safety and rights of people with ADRD and their care partners.
- 5a. Increase collaboration between health and legal service providers, for example, Legal Aid Society, the Alzheimer's Association Aloha Chapter, ADRCs, first responders, financial institutions, Adult Protective Services, law enforcement, Hawaii State Bar Association, Hawaii's Long-Term Care Ombudsman program, county prosecutors, and the Office of the Public Guardian.
- 5b. Collaborate with community partners to provide ongoing training and support for capacity assessments, advance care planning, Physician Orders for Life-Sustaining Treatment (POLST), Durable Power of Attorney for Healthcare, fiduciaries, mediation and family counseling, and guardianship and conservatorship proceedings in the Hawaii court system.
- 5c. Advocate for and support local and national policy efforts that strengthen the dignity, safety, and rights of people with ADRD and their care partners. For example, H.R.6813, Promoting Alzheimer's Awareness to Prevent Elder Abuse Act, passed the House of Representatives in October 2020. If enacted, this bill requires the Department of Justice (DOJ) to update best practices and other training materials specifically addressing victims and witnesses who have ADRD. These resources will be used to progress the dementia capability of law enforcement, judicial officials, and others whose work may bring them in contact with elder abuse.
- 5d. Develop stronger collaborations between Hawaii's Aging Network and Adult Protective Services. Institute statutory changes needed to uphold the dignity, safety and rights of people with ADRD and their care partners.
6. Improve safety for people with ADRD and their care partners.
- 6a. Target persons who live alone with dementia and educate them on fall prevention, as well as offering home safety assessments, and how to monitor those that wander from home.
- 6b. Ensure clear Federal Emergency Management Agency (FEMA) guidelines for evacuating and sheltering people with dementia and their care partners.
- 6c. Develop Hawaii's crisis capacity for care partners who are burnt out or ill, or when the person with dementia is having severe behavioral issues. Presently, there is little or no crisis intervention or safe and affordable emergency respite options in the state for these situations.

6d. Expand programs like Project Lifesaver, a project of the Hawaii Fire Department on Hawaii Island, statewide. The project’s mission is to provide timely response to save lives and reduce potential injury for adults and children who may wander due to Alzheimer’s, autism, and other related cognitive conditions.

6e. Develop artificial intelligence, remote monitoring, and other technology to help persons with dementia age in place.

6f. Create Silver Alert system in Hawaii, a program that sends out an alert to help find older adults who are missing.

6g. Address issues of loneliness and social isolation, particularly during the COVID-19 pandemic. One caregiver respondent to the Dementia Experiences Survey, indicated that:

*“It has helped and hurt. The senior free daily/ weekly meals have been a huge blessing for my father! But he really misses going out and hanging out at McDonald’s with a book. He feels lonely, he tells me, and would like someone to chat with.”*

#### ADVOCACY SPOTLIGHT

While no federal legislation coordinates the search of missing persons with ADRD, many states, including Hawaii, are exploring “Silver Alert” Systems. During the 2020 legislative session, Hawaii Senate Bill 3123 continued that effort, and although not enacted, advocates intend to continue their efforts during the 2021 Hawaii legislative session

#### **Goal 4: Enhance public awareness and engagement**

The public will be well-educated about brain health and dementia, risk factors, recognition of early signs of dementia, and behavioral issues – and are able to maintain good health practices and appropriately access resources when necessary. Public awareness of ADRD is one of the most recommended goals of all state, national, and global plans. The fear and stigma associated with dementia are compounded by a lack of knowledge and public education about the disease, its stages, the treatments, how to support caregivers, and where to get services.

#### Progress in Hawaii Since 2013

Hawaii has made substantial progress in improving public awareness about ADRD. First, the Alzheimer’s Association- Aloha Chapter’s ongoing mission is to raise awareness on the importance of early detection so that families can prepare and make long-term care and end-of-life decisions. A commercial aired by the Alzheimer’s Association, Aloha Chapter through

KHON from January - March 2019 resulted in a 72% increase in program contacts and a 57% increase in the number of physician referrals.

Second, the Alzheimer's Association also held a statewide series of community forums in 2018, which revealed updated insights into the unique challenges facing Hawaii'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 education on program on the basics of Alzheimer's and dementia, most participants were not confident in their understanding of the disease.

Third, with federal ACL funding provided to the COA, EOA, and CCH, there have been extensive efforts to promote dementia awareness and education in the state. The trainings targeted Hawaii's health care providers, including primary care providers, other allied health professionals, paraprofessionals, state agencies that are part of the No Wrong Door Network, and family caregivers statewide. 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. To accomplish this, the federal ACL grantees in Hawaii coordinated in-person and virtual trainings in partnership with the John A. Burns School of Medicine, Department of Psychiatry and Department of Geriatric Medicine's Geriatric Workforce Enhancement Program; Positive Approaches to Care certified trainers; Kokua Mau, a Hawaii non-profit organization which focuses on advance care planning, hospice, and palliative care; and the National Task Group on Intellectual Disabilities and Dementia Practices.

Another effort connects Hawaii to a global initiative to reduce stigma around dementia. Dementia Friends Hawaii, 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. The program is a partnership between Age-Friendly Honolulu and the UH Center on Aging's Hawaii Alzheimer's Disease Initiative. As part of the Dementia Friends curriculum, 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. Manoa Cottages in Kaimuki and Manoa have trained their staff in the Dementia Friends curriculum. Thus far, Dementia Friends Hawaii has trained nearly 1400

persons and has recently expanded to Kauai and is embraced by the Mayor and county directors. With funding from the National Asian Pacific Center on Aging (NAPCA), Dementia Friends Hawaii also collaborated to translate and pilot Dementia Friends with Chinese and Samoan churches on Oahu.

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 Kuike. PAC is a nationally recognized training developed by an occupational therapist and delivered via in-person, group sessions by a local certified trainer. The content focused on making positive connections, helping caregivers see more than just loss, addressing challenging behaviors, assisting with feeding and dining tasks, and preparing for the end of life. The focus is on providing family caregivers with the practical knowledge needed to keep their loved one with dementia at home and maintain their quality of life. 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.

**LOCAL RESOURCE**

Many people living in Hawaii do not speak English as their primary language, thus, public awareness and engagement efforts must consider the diverse language needs of the state. For example, EOA translated “Worried About Your Memory” into Ilocano, Japanese, Korean, Marshallese, Simplified and Traditional Chinese and Tagalog:  
<https://hawaiidrc.org/site/459/hadssp.aspx>

Updated Strategies

1. Think broadly about partnerships to assist in disseminating ADRD public awareness including:

<ul style="list-style-type: none"> <li>• Younger care partners (including child caregivers and millennial caregivers)</li> <li>• Former caregivers</li> <li>• Medical professionals, broadly defined (including, but not limited to Primary Care Physicians (PCPs), allied health professionals, pharmacists, formal caregivers)</li> </ul>	<ul style="list-style-type: none"> <li>• Office of Language Access</li> <li>• Schools/ students (including but not limited to health sciences, business, law, architecture, and engineering programs)</li> <li>• Transportation providers including, but not limited to The Bus, Handi Van, taxis, Uber, Lyft, non-emergency medical transportation providers</li> </ul>
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- Senior and respite companion programs
- Federally Qualified Health Centers
- Organizations and providers of persons with disabilities
- Financial institutions
- Bar Association
- Department of Parks and Recreation Senior Clubs
- Community organizations serving Native Hawaiian and Pacific Islander groups

- Grocery stores
- Emergency providers including, but not limited to law enforcement, fire fighters, first responders
- Faith-based community
- Resident managers and property managers

SPOTLIGHT: Human interest stories are a valuable awareness strategy. View this impactful story about Dr. Poki`i Balaz and her father at: <https://www.khon2.com/kupuna-life/kupuna-life-a-caregiver-for-the-ages/>



2. Employ creative methods and strategies to increase effectiveness and impact of dementia education.

2a. Increase culturally appropriate ADRD outreach.

2b. Share human interest stories broadly on web, TV, radio, print, and podcasts and utilize local celebrities with large followings.

2c. Create an intergenerational marketing campaign that is inclusive of all generations and identifies the impact of the disease on the entire family.

- 2d. Generate awareness among younger generations through digital games or apps as well as engagement of health science students as volunteers.
  - 2e. Target PCPs to normalize conversations about memory concerns and conduct regular cognitive screening.
  - 2f. Connect brain health messages to prevention of other diseases (e.g., connection between heart and brain health).
- 3. Build capacity for public education campaigns by identifying additional funding mechanisms, including private sector and corporate support.
  - 4. Identify critical ADRD messages to support families with ADRD at all phases of the disease, including: a) brain health; b) warning signs; c) early detection and diagnosis; d) steps after diagnosis; e) community resources and long-term planning; and f) special issues including living alone with ADRD and addressing stigma.

#### LOCAL SPOTLIGHT

Public awareness of support needed for care partners is paramount to a growing population of people living with ADRD. Encouraging care partners to prioritize their own health and well-being can be a challenge. A resource developed by the Alzheimer's Association, Aloha Chapter, helps increase awareness among care partners and provide encouragement to accept help through support groups: <https://youtu.be/JdUNAMgCFjw>

#### **Goal 5: Improve data to track progress**

Hawaii needs to identify measurable indicators to track progress in reaching its goals and objectives. Additionally, Hawaii should develop a system for collecting the data and monitoring the implementation of its action plan. Consistent sources of data can contribute to continuous monitoring, quality improvement, and guide programmatic and policy decisions.

#### Progress in Hawaii Since 2013

Steps have been taken to standardize and better understand the needs of persons with ADRD. First, an ADRD Data Advisory Team was established in 2019. EOA and COA partnered with the Telecommunications and Social Informatics Research Program/Pacific Health Informatics and Data Center (TASI/PHIDC) group at the University of Hawaii. The TASI/ PHIDC group analyzed the Hawaii-specific All-Payer Claims Database, which includes Medicare data for disease prevalence, healthcare services utilization, and costs.

Second, standardized dementia screening has been 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.

Third, federal funding has enabled EOA to purchase the cognitive decline module of the Behavioral Risk Factor Surveillance System (BRFSS). This Centers for Disease Control's national survey collects state-level data on health-related risk behaviors, chronic health conditions, and use of preventive services. Results from the 2020 BRFSS survey in Hawaii, including the cognitive decline and caregiver modules, will be available in 2021.

### Updated Strategies

1. Identify opportunities for improved data collection and analysis on ADRD in Hawaii.
  - 1a. Collaborate with agencies and organizations that have an interest in developing a better surveillance system for dementia.
  - 1b. Pursue continuous funding for data collection and analysis, including the administration of the cognitive decline and caregiver modules in the BRFSS survey.
  - 1c. Continue collaboration with UH TASI and their All-Payer Claims Database 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).
  - 1d. Expand partnerships to collect data from persons with dementia and their care partners and encourage participation from those underrepresented in research (for example, Native Hawaiians and other Pacific Islanders). Sources include but are not limited to: Physician offices (e.g. primary care physicians, audiologists), community health clinics (e.g. federally qualified health centers), churches, and community forums (e.g. AARP events).
  - 1e. Identify additional data sources to better understand the needs and issues of persons with ADRD, including: ADRD within Hawaii's Medicaid population, family caregiver costs, out-of-pocket ADRD expenses, quality of care/ life for the patient and care partners, and stress and well-being of ADRD families.
2. Use data effectively for continuous quality improvement and to inform providers, program development, and policy
3. Use data and evaluation to monitor progress on the implementation of the state plan and set new goals to further Hawaii's dementia capability.

### **Concluding Thoughts**

While all strategies are important, the feedback received throughout this update suggests stronger intersections are necessary between public awareness needs and all goals within the Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias. Strengthening the quality of and access to dementia capable LTSS by 2025 is paramount, however, denial and shame restrict many with early cognitive impairment from sharing cognitive concerns with providers. Even among ADRD providers, worry of one's own brain health was evident, suggesting that we need to continue increasing public awareness to challenge broad dementia stigma in our state.

*"Lately words do not come out as easily... [I'm] forgetting the right words to use or say. [I] get distracted easily and so forget what I was gonna do or what I went to the kitchen for,"* going on to share that she is worried about forgetting appointments and meetings.

-Powerful Tools for Family Caregivers support group facilitator worrying about her own memory

Stigmatizing attitudes of ADRD as a mental health diagnosis and cultural myths that normalize cognitive impairment will be difficult to overcome. Challenging this paradigm, however, EOA intends to continue statewide leadership and collaboration, inviting all systems that serve people living with ADRD and their caregivers to participate in making Hawaii more dementia-capable and making our communities more dementia friendly. EOA is also supporting and empowering families to better navigate and access support services, as evidenced by the Memory Care Roadmap for the Family Caregiver (See Appendix C).

### **Next Steps**

This report is an update for the 2021 Legislature, highlighting ADRD as a critical public health emergency and challenge for Hawaii's families. The next step is to conduct a full update of the state plan. In October 2020, EOA received a 3-year dementia planning grant from the Centers for Disease Control (CDC), as part of its "BOLD Public Health Programs to Address Alzheimer's Disease and Related Dementias" funding opportunity. The purpose of the opportunity is to align Hawaii's state plan with the CDC Healthy Brain Initiative Roadmap. Over the next several months, the EOA will contract with an ADRD coordinator using grant funds to begin grant planning activities. At the same time, during the 2021 Legislative session, EOA will advocate for full-time 1.0 FTE funding for the Alzheimer's Disease coordinator position and if approved, will hire a full-time ADRD coordinator.



With CDC funding, the ADRD coordinator will engage a diverse group of stakeholders to expand the Hawaii ADRD State Plan in order to:

- **Ensure inclusion and expand the use of effective interventions** by the Aging and Disability Resource Center (ADRC) sites and LTSS service providers.
- **Increase the number of sources of data** and ensure consistent reporting in order to ensure continuous quality improvement and the use of data to guide program and policy decisions
- **Improve knowledge** by healthcare professionals about the best available evidence on dementia, caregiving for persons with dementia, and available tools and supports.
- **Increase messaging and create tailored messages** targeted to different AAPI communities on the important role of caregivers.

Mahalo to stakeholders who have contributed to this state plan update. In the next several months, the EOA will re-engage stakeholders and expand stakeholder involvement to begin implementation of the CDC grant.

### **References**

1. Alzheimer's Association. Alzheimer's Disease Facts and Figures. Retrieved 10/28/20 from <https://www.alz.org/media/documents/hawaii-alzheimers-facts-figures-2018.pdf>
2. Alzheimer Dis Assoc Disord. 2015 Jan 24. [Epub ahead of print] PMID: 25626635

**Appendix A. List of ADRD Taskforce Members**

NAME	ORGANIZATION
Aida Wen, MD	University of Hawaii, JABSOM
Andrew Yeh, Ph.D.	University of Hawaii, Telecommunications and Social Informatics Research Program / Pacific Health Informatics and Data Center (TASI/PHIDC)
Dr. Brett Lu	University of Hawaii, JABSOM
Calvin Hara	Retired, Manoa Cottage
Christy Nishita, Ph.D.	Consultant, University of Hawaii, Center on Aging
Caroline Cadirao	Executive Office on Aging
Cristina Valenzuela	Executive Office on Aging
Dawn Meaney	Plaza Assisted Living
Debbie Shimizu	Executive Office on Aging
Diane Terada	Catholic Charities Hawaii
Dorothy Colby	Hale Kuike
Felicia Marquez-Wong	Retired, St Francis Hospice
Gary Simon	AARP Hawaii
Heather Chun	Consultant, University of Hawaii, Center on Aging
Ian Ross	Alzheimer's Association, Aloha Chapter
Ivy Castellanos	Alzheimer's Association, Aloha Chapter
Janie Tomihara	Retired, Department of Health, Public Health Nursing
Jody Mishan	Catholic Charities Hawaii
Kamal Masaki, MD	University of Hawaii, JABSOM
Katelyn Shirai	University of Hawaii, Student
Kathy Wyatt	Hale Hau'oli Adult Day Care
Kevin Kawamoto	University of Hawaii
Kore Liow, MD	Hawaii Pacific Neuroscience
Ku'unani Demante	Caregiver's Heart Hawaii
LJ Duenas	Alzheimer's Association, Aloha Chapter
Linda Axtell-Thompson	Policy Advisory Board on Elder Affairs (PABEA)
Lori Tsurada	Adult Protective Services
Lucas Morgan, Ph.D.	I Ola Lahui
Lyn Moku	Catholic Charities Hawaii
Mary Gadam	Retired, Department of Health, Public Health Nursing
Paige Heckathorn Choy	Healthcare Association of Hawaii
Poki'i Balaz, APRN	Lunalilo Home, Kokua Kalihi Valley
Ray Rice	Adult Protective Services
Ritabelle Fernandes	Kalihi Palama Health Center
Sean Okamoto	University of Hawaii, Telecommunications and Social Informatics Research Program / Pacific Health Informatics and Data Center (TASI/PHIDC)
Tricia Medeiros	Plaza Assisted Living



## Dementia Experiences in Hawaii

Hawaii first developed a **State Plan on Alzheimer's Disease and Related Dementias (ADRD)** in 2013. Five goals were identified: 1) Prevent and effectively treat dementia; 2) Enhance care quality; 3) Increase available support services in the community; 4) Enhance public awareness about dementia; 5) Improve data to track progress.

A lot has changed over the last seven years. To better prepare and identify opportunities to help persons with dementia and their caregivers, the Executive Office on Aging and UH Center on Aging would like to hear your thoughts and experiences with ADRD in order to update the plan.

Whether you are someone with dementia, a family member, a provider, or advocate, we would like to know how dementia has impacted you! Please complete this brief survey. Please feel free to share this survey with others as well.

**Please complete by August 31, 2020.**

1. First and Last Name (Optional)

2. E-mail address (Optional)

3. How has Alzheimer's Disease or related dementias affected your life or your work?

## Appendix B- Dementia Experiences Survey

4. What are you MOST concerned about (as someone with dementia, caring for someone with dementia, or a professional)?

5. What is the ONE CHANGE you would like to see in Hawaii in the future? (Dementia-related, of course!)

6. If you are a person with memory loss or a caregiver, what kind of help or support is most valuable to you (e.g., respite care, neighbor checking in)?

7. How has COVID-19 impacted you (as a person with dementia, caregiver, etc)?

8. (Optional) Tell us an uplifting personal story about your experience with dementia! Interested in sharing a photo with us (e.g., caregiving or other good work you do)? Please email to [uhcoa@hawaii.edu](mailto:uhcoa@hawaii.edu)

Thank you for sharing your feedback! Later this summer, UH Center on Aging will put together findings from this survey and input from our stakeholders to draft an update of the "Alzheimer's Disease and Related Dementias State Plan". We will then ask for community review and feedback on the updated plan before finalizing. If you have any questions, please e-mail [cnishita@hawaii.edu](mailto:cnishita@hawaii.edu)

**Appendix B. Dementia Experiences Survey- Highlights**  
**May to August 2020**

**Total Survey Responses from Persons with ADRD, Caregivers, and Professionals (n = 141)**

**Highlights and Quotes:**

**1. Feedback from those living with ADRD**

- Concern about future disability
  - “My aging mind is still okay but it is becoming more challenging to engage in complex mental tasks and I’m concerned about possible future disability.”
  - Concerned about: “Being able to make competent decisions and managing to be self-sufficient in running my affairs”
- Concern about daily tasks
  - “Lately words do not come out as easily. . .in other words, forgetting the right words to use or say. Get distracted easily and so forget what I was gonna do or what I went to the kitchen for.”
  - Concerned about: “medication and keeping appointments”
  - “Family education, for the young as well, to understand why grandma/grandpa acts the way they do. Not to be afraid being around people with dementia.”
  - “Isolated and lack of activities for this active senior, stress and frustration on a high level.”
- Interest in supporting others with ADRD
  - From Powerful Tools for Family Caregivers program facilitator sharing positive aspects of the program: “...having participants know that they are NOT alone. Sharing of stories and experiences builds the confidence that they can do it!”

**2. COVID-19 Impacts**

On person with ADRD

- Increased anxiety and confusion
- Lacking understanding on proper mask wearing and need for increased sanitation
- Social isolation/ lack of stimulation
  - For those living at home
    - “It has helped and hurt. The senior free daily/ weekly meals have been a huge blessing for my father! But he really misses going out and hanging out at McDonald’s with a book. He feels lonely, he tells me, and would like someone to chat with.”
    - “So far, I have not been impacted by COVID-19 and I'm trying to be very careful to avoid this disease.”
  - For those living in long-term care facilities
    - “Restricted Visiting policy at facilities and care homes on lockdown.”

## Appendix B. Dementia Experiences Survey- Highlights

May to August 2020

- "...a good friend was not able to visit her mother dementia. And although her mother was already frail, not visiting her mother added to her mother not eating and failure to thrive."
- "My family is not allowed to see my grandma [with dementia] who lives in a care home. We take her out every weekend for lunches but are unable to. We will miss her birthday, but technology will allow us to see her, just not hug her."
- "I have not been able to visit my loved one in a care home."
- "I was deemed essential at the onset of the COVID-19 epidemic, so I've been at work every day throughout. I was prohibited from seeing my father in his nursing home because of the pandemic, and he died there alone, 2 months ago."
- Increased hospitalizations
  - "My clients have had fewer outings, less contact with immediate family. My clients have fewer outlets to reduce their pre-existing mental health conditions and have had multiple hospitalizations due to lack of coping skills available to them." Case manager (who also has experienced ADRD with grandparents earlier in life)

### On Caregivers

- Caregivers feeling their own social isolation, decreased mental health, and increased anxiety and doubt in ability to provide adequate care
  - "My Mom hasn't been out of our house since March 20. Her day care is closed. She used to attend twice a week. I've only been out twice, once to take a blood test and once to go to the bank. Both times I was able to go out because a cousin came in to watch Mom."
  - "My sister in the Mainland tries to help. She does a FaceTime session with Mom each day for 1-2 hours, so I can get some rest. They sing, talk and count. My sister tries to get Mom to do some kind of craft, like tying bows with ribbon. Mom doesn't always cooperate, but my sister keeps trying. It's a real help."
  - "My mother's Adult Day Health Care Program is closed and has been since March. I've had to keep my mother at her home and provide 24/7 care with the help of caregivers along with continuing to work full time at my current job."
  - "Meals on Wheels. This was stopped due to COVID pandemic and is sorely missed."
  - "Limited accessibility to health care and groceries are major issues that everyone are dealing with during the COVID-19 pandemic. I believe that caregivers are most affected as they have to deal with both their loved ones and self."

**Appendix B. Dementia Experiences Survey- Highlights**  
**May to August 2020**

- “In order to keep my parent safe, family caregivers must keep themselves fairly isolated as well. Lack of stimulation for parent whose only outing is to go on rides w/o getting out of the car. Have had many Dr. appts. cancelled. Will see how well the telehealth works.”
- “Allowed me and my sister to work from home, making it easier for other caregivers to have us here. It will be difficult for everyone, when we have to work from our offices.”
- “I am reluctant to see elders in my family in their homes for fear of exposing them to COVID-19. But, distancing myself from my family elders has an emotional price for me.”

**On Professionals:**

- Professionals faced numerous challenges in providing care and facing closures of worksites.
  - “I can only service half my clients, as to stay 6 feet apart! Daily!” – Malama Adult Day Care service provider
  - “Our adult day center had to close for 3 1/2 months during COVID-19 and laid off 27 employees (re-opened July 1, 2020) Our caregivers had to care for their loved ones with dementia, etc. during this time 24/7 without any form of respite. We were in contact with our caregivers during this time and while they managed, they could hardly wait until we opened again. We have seen some diminished conditions of some of our participants as they returned to the center.”
  - “As a nursing home social worker, COVID -19 has added more job stress and anxiety over keeping the virus away and my clients safe. Also having to go to work every day, hoping not to get the virus or unknowingly being a carrier.”
  - Virtual engagement has made it challenging to assess functional changes
  - “Remote assessments, relying on caregivers to be honest communicators for seniors needs, when they may have an agenda or lack of awareness or understanding about disease or person needs.”
  - “We have more people in the hospital, whose families could not keep them in the home (they would just leave, because they do not understand COVID-19 and staying home. We also have had no services for patients and families.” – hospital social worker
  - “We have had to decide who could come back to the Center and who could not. Those that would not sit in their 6ft. space and wants to touch everything and everyone. Those that drool (bodily fluids). Most dementia people will not keep their masks on. Constant cleaning where they've touched.” – Adult Day Care specializing in memory care
  - “Limited home visits and facilities not accepting new clients as residents. COVID-19 testing protocols for admission vary.”

**Appendix B. Dementia Experiences Survey- Highlights**  
**May to August 2020**

- “As a member of the ADRC team, we focused on helping people not to feel isolated. Had some success connecting people with Dementia and their caregivers to support groups via video communication.”
- “COVID-19 has limited our ability to provide direct Public Health Nursing services.”
- “COVID-19 has slowed ability to support persons with dementia and their family caregivers, because of the restriction on PHN home visiting. Caregivers have been left with little support, in absence of the adult day care, which closed due to COVID 19 March 23-June 1, 2020. Many assigned in-home staff caregivers had to stay home with school-age children when schools closed, diluting the already strained homebased agency caregiver pool. People kept coming out of the hospital needing home services, or declining in function during the COVID-19 shutdown months, but our capacity to assist them has been limited, and elders living in unsafe conditions have proliferated. "early dementia can live alone with adequate support services". In absence of adequate service providers, able to visit homes regularly, early dementia patients have been at risk.” – Public Health Nurse, West Hawaii
- “We have seen an increase in the amount of referrals to do "Welfare Checks" on vulnerable seniors with medical issues and dementia that either are staying at home to avoid COVID-19 or who are making poor decisions r/t dementia and going out to seek services. Unfortunately, with COVID-19, we could not do a lot for these clients and there were very few resources to help these clients.”
- “The senior center I am the head of has closed, so we have had to offer online classes to seniors. However, many of them do not have computers or smart phones to access such programming. We are making phone calls to every senior center member and mailing birthday cards to keep their spirits high and to assist them to fulfill their basic needs and connect them with community services. It is a time that the human spirit shines brightly with the kindness, appreciation, and thoughtfulness shown by seniors and their families, the community and our staff.”
- “Severely complicated face-to-face interactions which result in heightened anxiety on the part of those with dementia conditions.”

**3. Uplifting Stories and ADRD Experiences**

From Caregivers:

- “It definitely gives my life a sense of purpose. It has led me to focus more on the present moment and enjoy it. It has also led me to focus more urgently on the spiritual than the temporal, realizing how fragile and changeable our life circumstances are. This makes me a more stable person.”



**Appendix B. Dementia Experiences Survey- Highlights**  
**May to August 2020**

- “When the one you give care to, looks you square in your eyes, recites your name, and tells you how much they love you and appreciate all you do for them (which is giving them the care they need, with love, respect, understanding, and patience).”
- “My father's change in personality with Alzheimer's had a special silver lining to the cloud.....despite all the horrid and strange and odd and scary and sad, mad and bad behavioral changes, he also became much more expressive, open and sharing of his feelings and love for me. My father was raised in a strict catholic New England family where there was no showing of affection. His hugs were more of a distant “pat pat” on the back. I could count on 2 fingers how often he had told me he loved me through the 55 years before his Alzheimer's set in. As his Alzheimer's progressed, he became more and more affectionate, to the point that when I would enter the room, he's jump up out of his chair, raise his arms up in the air and say "oooooh, you're here, you're here!" and then put out his arms for a big hug. And when I'd tell him I loved him, he'd finally tell me he loved me too.”
- “A good friend and former parish nurse, set up a rotation with six people who each came by to take my Mom on an outing each week, based on what they liked doing. One would take her to a lunch and matinee. Another to the art museum, another on a drive to Kailua to see the beauty of the mountains, ocean, trees. When it was hard to take Mom out, some chose to visit her at our home. One read her Winnie the Pooh stories, another brought lunch and they watched the Three Tenors DVD multiple times. It was quite precious. She couldn't recall later what she'd done but in the present, she was elated.”
- “Since my partner can't remember to worry he wakes up happy and care free and he always tells me how great life is.”
- “Given that my grandmother took care of me, it was not just an exhausting experience, but the most rewarding experience ever being able to care for her. It made me see things differently, humbled me.”
- “My grandma was lucky enough to have a strong support system of 4 caring children. Seeing all the family members come together to help care and take her on outings was special to see because we lacked that connection and closeness when grandpa died in 2011. It was a silver lining that her [dementia] brought the family together. Even though she is now in a care home, after living with family for 10+ years, we are closer and initiate more family gatherings besides holidays (Card night). Of course, COVID-19 put a stop to that, but we are looking forward to when a vaccine is created.”
- “Alzheimer's Association has been a life savor in numerous situations!!”
- “I was caregiver for my Mom. Growing up we were a dog family and Mom hated cats! Every time my best girlfriend's cat would have kittens, she would beg my Mom to let me have one. When Mom came to live with me, her dementia allowed her to forget that she hated cats and she absolutely loved to watch my cat play and loved it when he would curl up on her lap.”

**Appendix B. Dementia Experiences Survey- Highlights**  
**May to August 2020**

- “A strange and wonderful thing happened to my [sister] who had had a left- brain stroke affecting speech. She began getting lost in her daily routine forgetting what to do. She was put on Alzheimer’s meds, [which improved] her speech that was affected by the stroke, amazingly improving [her] enunciation and sentence structure.”
- “The last thirteen years of my mother's life were the best years of our relationship. She lived in a foster home for ten years before passing. She had excellent care and was treated as a family member (the entire family called her "mother.") My visits with her were spent driving all over the island; going to restaurants; eating anything she wanted to eat; and talking for hours while she listened and smiled. I set and combed her hair; gave her manicures and massages; held her hands; and kissed her all over her face when I left to go home. The grandkids would visit her, sharing their coloring books with her and arguing over who the toys belonged to. We had tea parties; wore birthday tiaras and laughed so hard we cried. For the first time in her life she had no worries and that was a good thing. She was always smiling and seemed genuinely happy. We didn't think about AD as time went on. We just enjoyed the time together and were left with wonderful memories.”
- “The staff at the home kept telling me what bad shape my mother's memory was in. It was discouraging. Then last February, as I sat with her and the staff was adjusting the TV, mom & I were having a chat about shows, my Mom made her comments in Spanish and the staff immediately became attentive! "I didn't know you could speak Spanish" ..worker said. I replied yes my mom taught herself Spanish years ago to help at work and funny huh she remembers how to comment to you in another language. It showed me you can't rule an old person out by their outer appearance. I hoped it showed staff too not to assume things. Mom died in May at 102.5 years old.”
- “Mom was 96 when she passed away. Gratefully, despite the decline from the disease, she maintained a sweet and calm disposition, often expressing her gratitude for everyone's care and help. She was able to engage in (relatively lucid) conversation and could sing along with songs from early days. HAPPY BIRTHDAY song was a favorite and sung often at Hale Malamalama and one day after the group sing-a-long, one of the staff randomly wished Mom happy birthday. From what I understand, Mom thought about it, then asked the staffer if it really was June 20 (her birthday.) It wasn't! Think staff were surprised that that had bubbled up from her long term memory. We are very grateful that dementia never robbed us of Mom's personality or clouded her memory so much that she lost her connection to us, especially to Dad. Until the end, Mom knew him by name, knew he was her husband and would express disbelief when reminded that she'd been married to the same man for 70 years. Know that this brings Dad some comfort everyday.”
- “I am amazed at my mother's approach to her situation. Note it is complicated by a back injury that has he wheelchair bound. She rarely complains, she is appreciative of

**Appendix B. Dementia Experiences Survey- Highlights**  
**May to August 2020**

all that we do and I am amazed by her resiliency. An amazing woman, mother, grandmother and great- grandmother. Love you mom!!”

- “Although my mother-in-law lived for decades with ADRD and my wife sacrificed her career and earnings and retirement benefits, we would take the journey all over again. The wisdom passed on from my mother-in-law to our extended family members is a legacy treasure. The keiki in our extended family developed a remarkable depth of compassion in being caregivers for years to one of their beloved kupuna.” – from a caregiver who lived with his mother-in-law with ADRD for more than 25 years (from 1994 to 2019). His, “wife quit her career in 1994 to provide around the clock support to her mom, who died in our home in 2019.”

From Professionals:

- “Two gentlemen who were moderate to late Alzheimer's that knew each other but never socialized together, were put with a caregiver who took them riding weekly. They both talked nonstop the whole entire time like best friends, and yet would not have said more than hello previously. I have seen pairing that would never have imagined that were perfect together at this time in their journey. Never can assume anything and everything is possible just don't give up!”
- “We take Miniature Horses to Long Term Care facilities to visit with their residents...It is the highlight of their week.”
- “We are caregivers. we take care of dementia clients all day every day. We find the most rewarding times are during those moments of clarity when they come through with an appropriate statement like ‘thank you for being so kind to me’ or ‘thank you for taking care of me’ or ‘did you know this is my favorite song’ or ‘you have a beautiful voice’.” - Adult Day Care specializing in memory care
- “As fellow caregiver, I feel uplifted when I can help caregiver in the thick of it take a breath and appreciate the experience and time they are having with their loved one. Help them recognize that time with their loved one is limited commodity and enjoy all it while it lasts. Helping them recognize and re-frame caregiving as opportunity to create memories for themselves and experiences for their loved one that they can look back with joy and fondness and pride.”
- “There are seniors who let me know of their concerns with their growing inability to remember things, but they are proactive and want to seek out activities that help exercise their brain. The warmth and sweetness of these older adults even with what is happening to them is evident and endears all they interact with. I love and care about them.” – self identified as the head of a local senior center.

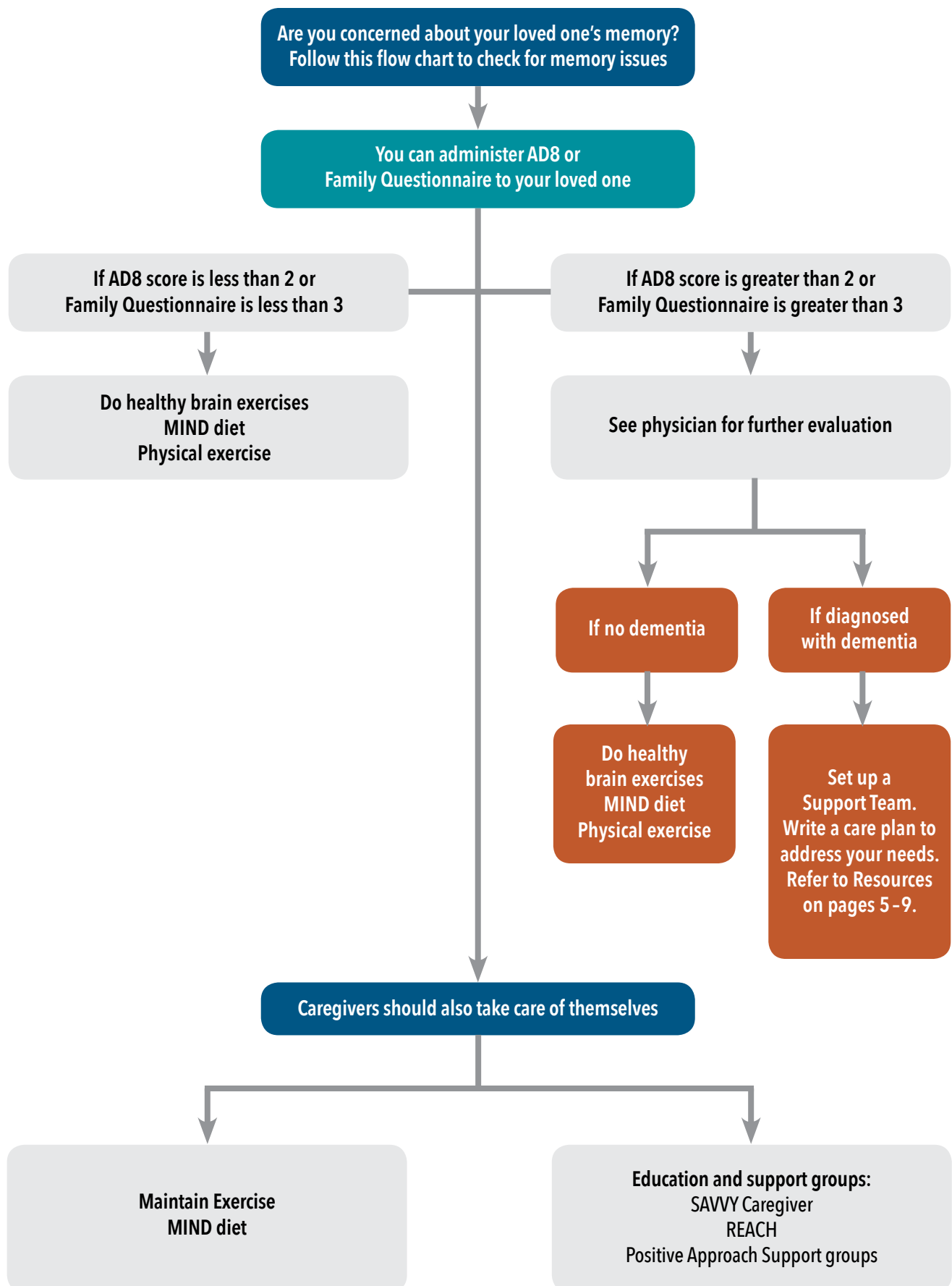


# **Memory Care Roadmap** for Family Caregivers

*A Guide for Families Caring for Their Loved One with Dementia*

# Roadmap for Family Caregivers

## COGNITIVE SCREENING FLOW CHART



# Roadmap for Family Caregivers

## DEMENTIA SCREENING TOOLS

### AD8 Dementia Screening Interview

Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.	YES, A change	NO, No change	N/A, Don't know
1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)			
2. Less interest in hobbies/activities			
3. Repeats the same things over and over (questions, stories, or statements)			
4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)			
5. Forgets correct month or year			
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)			
7. Trouble remembering appointments			
8. <b>Daily</b> problems with thinking and/or memory			
<b>TOTAL AD8 SCORE</b>			

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, *Neurology* 2005;65:559-564. Copyright 2005. The AD8 is a copyrighted instrument of the Alzheimer's Disease Research Center, Washington University, St. Louis, Missouri. All Rights Reserved.

#### The AD8 Administration and Scoring Guidelines

- A spontaneous self-correction is allowed for all responses without counting as an error.
- The questions are given to the respondent on a clipboard for self-administration or can be read aloud to the respondent either in person or over the phone. It is preferable to administer the AD8 to an informant, if available. If an informant is not available, the AD8 may be administered to the patient.
- When administered to an informant, specifically ask the respondent to rate change in the patient.
- When administered to the patient, specifically ask the patient to rate changes in his/her ability for each of the items, **without** attributing causality.
- If read aloud to the respondent, it is important for the clinician to carefully read the phrase as worded and give emphasis to note changes due to cognitive problems (not physical problems).
- There should be a one second delay between individual items.
- No timeframe for change is required.
- The final score is a sum of the number items marked "Yes, A change".

Scoring criteria = Scores in the impaired range (see below) indicate a need for further assessment. Scores in the "normal" range suggest that a dementing disorder is unlikely, but a very early disease process cannot be ruled out. More advanced assessment may be warranted in cases where other objective evidence of impairment exists.

- 0 - 1: Normal cognition
- 2 or greater: Cognitive impairment is likely to be present

### Family Questionnaire

In your opinion does \_\_\_\_\_ have problems with any of the following?

Please circle the answer.

1. Repeating or asking the same thing over and over?	Not at all	Sometimes	Frequently	Does not apply
2. Remembering appointments, family occasions, holidays?	Not at all	Sometimes	Frequently	Does not apply
3. Writing checks, paying bills, balancing the checkbook?	Not at all	Sometimes	Frequently	Does not apply
4. Deciding what groceries or clothes to buy?	Not at all	Sometimes	Frequently	Does not apply
5. Taking medications according to instructions?	Not at all	Sometimes	Frequently	Does not apply

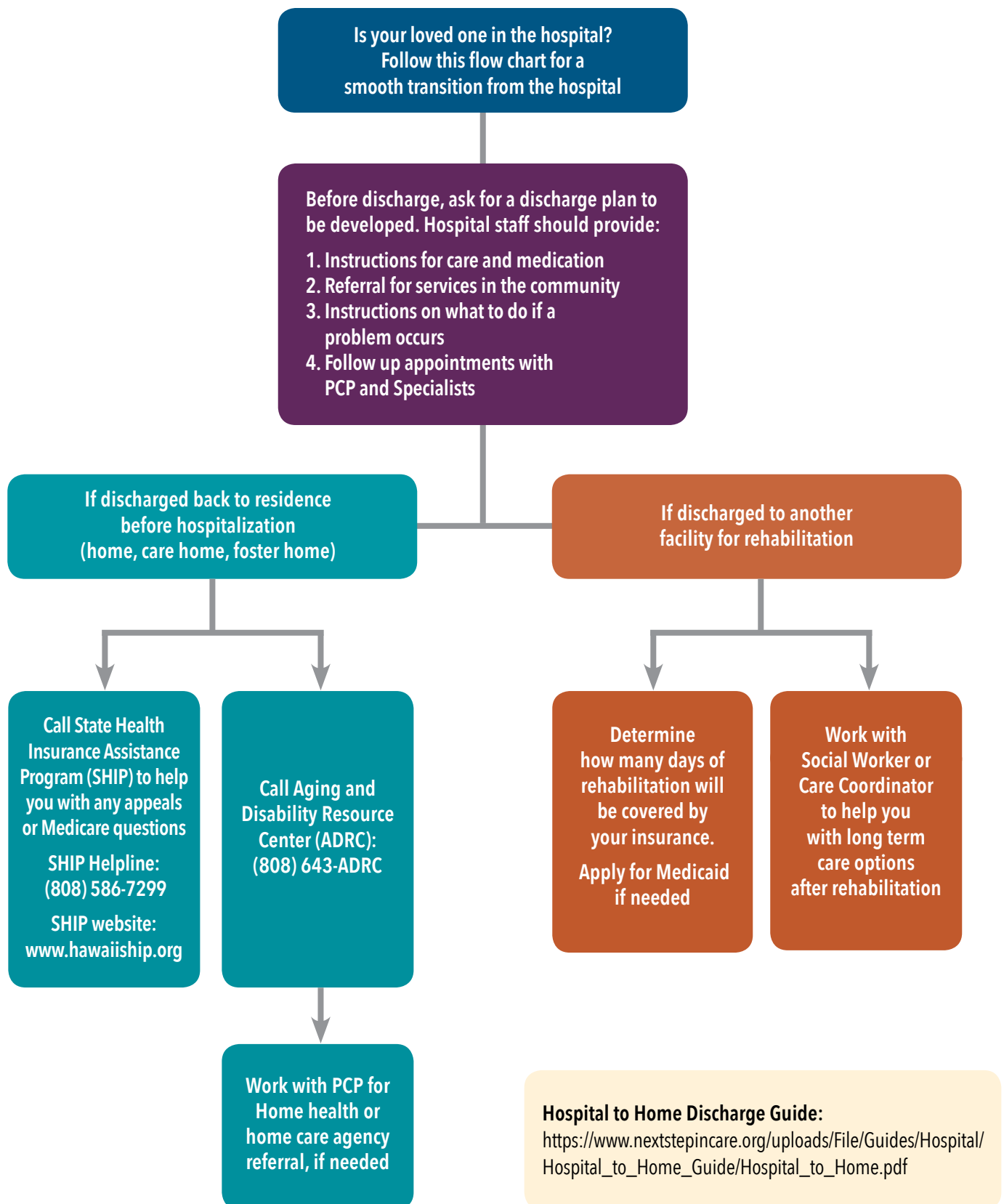
Relationship to patient \_\_\_\_\_ (spouse, son, daughter, sister, grandchild, friend, etc.)

Scoring: Not at all=0, Sometimes=1, Frequently=2. Sum to get total score. A score of 3 or more should prompt the consideration of a more detailed evaluation

\*Adapted from the Care Management Advisory Group of the Chronic Care Networks For Alzheimer's Disease Initiative. Full version from: (<https://www.alz.org/documents/national/CCN-AD03.pdf>)

# Roadmap for Family Caregivers

## HOSPITAL DISCHARGE FLOW CHART





# Roadmap for Family Caregivers

## GUIDE TO CHOOSING CARE OPTION

### A Caregiver's Guide in Choosing a Care Option

#### Introduction

Caregiving can be stressful and overwhelming for many families. Sometimes seeking outside help can be lifesaver for a caregiver. The extra assistance can help prevent caregiver's burnout while providing the kind of care that may be beneficial to the person with dementia. When searching for the appropriate service, caregivers may want help from a professional advocate to navigate our long-term care system which can be complex and confusing for many. Caregivers can contact the local county Area Agency on Aging (AAA) that is available in each county. They provide free information and referrals to the public. It is also the designated Aging and Disability Resource Center (ADRC), the one stop shop for information and resources for seniors, people with disabilities and family caregivers. The public may call the statewide number 643-ADRC (2372) or visit their website – [www.HawaiiADRC.org](http://www.HawaiiADRC.org) to be connected to their local AAA/ADRC. The AAA/ADRC staff will assess the caller's needs and help identify the different options available in the community.

#### Options for In-home care

In-home care can help people continue to live independently or with family. Services range from weekly household chores to extensive overnight care. There are two types of in-home care:

1. **Home health care** - Home health care is required if your loved one has extensive medical needs (tube-feeding, medication administration, wound dressing change). A licensed staff (registered nurse or licensed practical nurse) is required to perform skilled nursing care. The fees for Licensed nurses range from \$30-50/hour.
2. **Home care** - Home care helps with personal care (bathing, grooming), meal preparation, light housekeeping, companionship, etc. Most individuals can be assisted by a home care aide or certified nurse aide whose rates range from \$20-25/hour. Many home care agencies have a minimum requirement of 2-4 hour of services and charges a one-time assessment fee. The agency will develop a plan of care based on the client and family's needs.

Home Care guide: [https://www.nextstepincare.org/uploads/File/Guides/Home\\_Care/Guide/Home\\_Care.pdf](https://www.nextstepincare.org/uploads/File/Guides/Home_Care/Guide/Home_Care.pdf)

#### Options for Out-of-home Care

There is a wide range of home and community-based programs for individuals with dementia. Some services offer care during the day, while others can provide 24-hour coverage in the person's home, and/or full-time residence. Some families use a combination of in-home care and out-of-home care such as adult day care to provide the extra assistance needed especially if they are working caregivers with jobs. These are some out-of-home care options:

- Adult Day Care Center
- Adult Day Health Center  
(for those who need more assistance during the day)
- Adult Residential Care Homes
- Foster Family Care Homes
- Assisted Living facilities with memory support units
- Nursing Homes

These facilities are designed to help individuals who are in varying stages of dementia. People can participate in a day care program for many years before gradually requiring more medical attention that can be provided by an adult day health center which has licensed nurses. Residential facilities assist individuals who can no longer reside safely in their own homes. Some assisted living and nursing homes offer temporary respite beds for caregivers who need a short break or a vacation. Nursing homes provide extensive medical supervision and extra help for individuals who need more care. Nursing homes are the most expensive long-term care service.

#### Tips for Selecting a Long-Term Care Provider or Facility trained to provide care for persons with Dementia

- ✓ Ask if the agency/organization provides services or supports to persons with memory loss or dementia
  - If yes, find out if they have any restrictions or limitations in serving those in advanced or late state dementia or with individuals with challenging behaviors related to dementia such as wandering or aggressive behaviors.
  - Ask if the staff has received dementia-specific training
- ✓ Ask about security measures to prevent wandering offsite, and search protocol for elopement
- ✓ Families have the option to ask for another caregiver if not compatible with the dementia client. Sometimes, people interact better with different types of personalities



# Roadmap for Family Caregivers

## DEMENTIA RESOURCES

Visit the Aging and Disability Resource Center (<https://www.hawaiiadrc.org>) for additional resources and information.

Note: Inclusion of an agency/organization in this Roadmap does not imply endorsement by HADSSP

### Help with Diagnosis and Behavior Management

#### Refer to Specialist as Needed

- Neurologist (dementia focus, if possible) <https://www.hawaiiadrc.org/site/459/hadssp.aspx>
- Geriatric Psychiatrist, <https://www.hawaiiadrc.org/site/459/hadssp.aspx>
- Geriatrician (A doctor who specializes in treating conditions that affect older adults), <https://www.hawaiiadrc.org/site/459/hadssp.aspx>
- Information on stages & behaviors, <https://www.alz.org/care/alzheimers-dementia-stages-behaviors.asp>

#### Link to Caregivers Support Groups

##### Hawaii (Big Island)

- Alzheimer's Association Support Group, (800) 272- 3900, [www.alz.org/crf](http://www.alz.org/crf)
- Big Island Stroke Club, 1190 Waianuenue Avenue, Hilo Medical Center (The Learning Center), Hilo 96720, (808) 932-3045

##### Kauai

- Alzheimer's Association Support Group, (800) 272- 3900, [www.alz.org/crf](http://www.alz.org/crf)

##### Maui

- Alzheimer's Association Support Group, (800) 272- 3900, [www.alz.org/crf](http://www.alz.org/crf)
- Powerful Tools for Caregivers (UH Manoa Extension), 310 Ka'ahumanu Ave., Bldg. 214, Kahului 96732, (808) 244-3242 x226

##### Oahu

- Alzheimer's Association Support Group, (800) 272- 3900, [www.alz.org/crf](http://www.alz.org/crf)
- Castle Caregiver Support Group, (808) 263-5400
- Hale Hauoli Hawaii-Caregiver Support Group, 98-1247 Kaahumanu St., Suite 207, Aiea 96701, (808) 292-4665, [www.halehauolihawaii.org](http://www.halehauolihawaii.org)
- Kokua Kalihi Valley Caregiver Support, 1846 Gulick Ave., Honolulu 96819, (808) 791-4900, [www.kkv.net](http://www.kkv.net)
- Caregivers Foundation Support Group, Various Locations, (808) 625-3782, [www.thecaregiverfoundation.org](http://www.thecaregiverfoundation.org)
- Project Dana, Caring for the Caregiver Support Group, 902 University Ave., Honolulu 96826, (808) 945-3736, [www.projectdana.org](http://www.projectdana.org)
- VA Caregivers Support Group, 459 Patterson Rd., Honolulu 96819, (808) 433-7646
- Windward Seniors Day Care-CG Support Group, 77 N. Kainalu Dr., Kailua 96734, (808) 261-4947, [www.windwardseniordaycarecenter.org/resources.html](http://www.windwardseniordaycarecenter.org/resources.html)

#### Link to Community Resources

- Contact the Alzheimer's Association – Aloha Chapter 24/7 Helpline at 1-800-272-3900 or [www.alz.org/hawaii](http://www.alz.org/hawaii)
- Contact Hawaii Aging and Disability Resource Center (ADRC)\* statewide at 643-ADRC (2372) TTY line: 643-0889. Or, go to [www.HawaiiADRC.org](http://www.HawaiiADRC.org) and click on "Professionals & Service Providers"
- Alzheimer's and Dementia Caregiver Center, [www.alz.org/care/](http://www.alz.org/care/)
- TrialMatch®, [www.alz.org/trialmatch](http://www.alz.org/trialmatch)
- Life After Diagnosis, [www.alz.org/alzheimers\\_disease\\_life\\_after\\_diagnosis.asp](http://www.alz.org/alzheimers_disease_life_after_diagnosis.asp)
- Taking Action Workbook, [www.actonalz.org/pdf/Taking-Action.pdf](http://www.actonalz.org/pdf/Taking-Action.pdf)
- NIH Caring for a Person with Alzheimer's Disease, <https://www.nia.nih.gov/alzheimers>

### Counseling, Education, Support & Planning

\*The Hawaii Aging and Disability Resource Center (ADRC) helps older adults, individuals with disabilities, and family caregivers find options for long term supports and services available to them in the State of Hawaii.

# Roadmap for Family Caregivers

## DEMENTIA RESOURCES - Continued

### Counseling, Education, Support & Planning (cont'd)

#### **Link to Community Resources (cont'd)**

- Contact Case Management Services, By County/Statewide, 643-ADRC (2372), [www.HawaiiADRC.org](http://www.HawaiiADRC.org)
- Contact Home Care/In Home Assistance, By County/Statewide, 643-ADRC (2372), [www.HawaiiADRC.org](http://www.HawaiiADRC.org)
- Contact Adult Day Services, By County/Statewide, 643-ADRC (2372), [www.HawaiiADRC.org](http://www.HawaiiADRC.org)
- Contact Respite Services, By County/Statewide, 643-ADRC (2372), [www.HawaiiADRC.org](http://www.HawaiiADRC.org)
- Check if Home Care agency, Adult Day Services or Long Term Care Facility is licensed, <https://health.hawaii.gov/ohca/state-licensing-section/>

#### **Link to Education Resources**

- Online Education Programs - Presented by the Alzheimer's Association-Hawaii, 1-800-272-3900, [www.alz.org/hawaii/](http://www.alz.org/hawaii/)
- Online Program Descriptions - Presented by the Alzheimer's Association-Hawaii, 1-800-272-3900, [www.alz.org/hawaii/](http://www.alz.org/hawaii/)

### Stimulation/Activity/ Maximizing Function

- Living Well Workbook, [www.actonalz.org/pdf/Living-Well.pdf](http://www.actonalz.org/pdf/Living-Well.pdf)
- Adult Day Services, By County/Statewide, 643-ADRC (2372), [www.HawaiiADRC.org](http://www.HawaiiADRC.org)
- Sensory aids (hearing aids, pocket talker, glasses, etc.), [www.HawaiiADRC.org](http://www.HawaiiADRC.org) or 643-ADRC (2372)
- NIH's Caring for a Person with Alzheimer's Disease, <https://www.nia.nih.gov/alzheimers>
- Exercise for Frail and Disabled Elders, By County/Statewide, 643-ADRC (2372), [www.HawaiiADRC.org](http://www.HawaiiADRC.org)
- Audient - Affordable Hearing Aids, 1-866-956-5400, [www.audientalliance.net](http://www.audientalliance.net)
- Hearing Aid Helpline, 1-800-521-5247, [www.ihsinfo.org](http://www.ihsinfo.org)
- Seniors EyeCare Program, [www.eyecareamerica.org](http://www.eyecareamerica.org)
- Assistive Technology Resource Center Hawaii, 200 N. Vineyard Blvd, Honolulu 96817, (808) 532-7110, <https://www.atrc.org>

### Medication Therapy and Management

- Family oversight or health care professional monitoring
- Identify all medications, including over-the-counter medications, vitamins and herbal remedies
- Educate patient and care partner on medication management aids (pill organizers, dispensers, alarms)
- Use a tool like "Tracking Your Medication Worksheet" and share the list with the healthcare team <https://www.nia.nih.gov/health/tracking-your-medications-worksheet>
- Medicine, Age, and Your Brain, <https://www.nia.nih.gov/sites/default/files/d7/MedAgeBrain-FactSheet.pdf>
- Medicare Part D, <https://www.medicare.gov/drug-coverage-part-d>
- Hawaii SHIP-Eligibility and help choosing a health plan, <https://hawaiiiship.org> (808) 586-7299, 1-888-875-9229
- Med-QUEST Division (Medicaid), Eligibility Branch Offices - County, <https://medquest.hawaii.gov/en/resources/med-quest-offices.html>

### Cultural Resources & Language Services

- Screening diverse populations, <https://actonalz.org/screening-diverse-populations>
- HADI culturally competent resources, [www.hawaii.edu/aging/coa-projects-all/hadi-project/hadi-resources/](http://www.hawaii.edu/aging/coa-projects-all/hadi-project/hadi-resources/)
- For materials in different languages, go to Alzheimer's Association ([www.alz.org](http://www.alz.org)), scroll down to the bottom of the page and click on "Select Language".
- Bilingual Access Line (24-Hours) - Helping Hands Hawaii, 2100 N. Nimitz Hwy, Honolulu 96819, (808) 526-9724, [www.helpinghandshawaii.org](http://www.helpinghandshawaii.org)

# Roadmap for Family Caregivers

## DEMENTIA RESOURCES - Continued

### Safety

*Note: Individuals with dementia are vulnerable adults and may be at a higher risk for elder abuse and exploitation.*

### Driving

- Refer to driving rehab specialist/occupational therapist for clinical and/or in-vehicle evaluation
- Understanding Dementia and Driving, <https://www.thehartford.com/resources/mature-market-excellence/dementia-driving>
- At the Crossroads Guidebook, [https://s0.hfdstatic.com/sites/the\\_hartford/files/cmme-crossroads.pdf](https://s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf)
- Dementia and Driving Resource Center, [www.alz.org/care/alzheimers-dementia-and-driving.asp](http://www.alz.org/care/alzheimers-dementia-and-driving.asp)
- Fitness to Drive Screening Tool, <https://www.aarp.org/auto/driver-safety/info-2013/fitness-to-drive-screening-tool.html?migration=rdrct>
- Rehab Hospital Driving Evaluation and Training Program, 226 N. Kuakini St., Honolulu 96817 (808) 566-3762, [www.rehabhospital.org](http://www.rehabhospital.org)

### Fall Prevention

- Preventing Falls Among Older Adults, <https://health.hawaii.gov/injuryprevention/home/preventing-falls/information/>
- Refer to an occupational therapist and/or physical therapist to address fall risk, sensory/mobility aids and home modifications
- Project Dana Fall Prevention Program, 902 University Ave., Honolulu 96826, (808) 945-3736, [www.projectdana.org](http://www.projectdana.org)
- Connect America (Medical Alert System), 98-030-Hekaha St. #4 Aiea 96701, (808) 721-1201, [www.connectamerica.com](http://www.connectamerica.com)

### Wandering

- MedicAlert® and Alzheimer's Association 24/7 Wandering Support, <https://www.alz.org/help-support/caregiving/safety/medicalert-with-24-7-wandering-support>
- Six out of 10 People With Alzheimer's Will Wander, <https://www.alz.org/help-support/caregiving/stages-behaviors/wandering>
- Wandering and Getting Lost, [www.alz.org/care/alzheimers-dementia-wandering.asp](http://www.alz.org/care/alzheimers-dementia-wandering.asp)

### Legal/Financial

- Encourage patient, as appropriate, to include designating an agent and an alternate agent in a durable power of attorney for health care decisions and to designate an agent or alternative agent in a durable power of attorney for legal and financial matters.
  - UH Elder Law Program Health Care Decision Making, [www.hawaii.edu/uhelp/elderlaw.htm](http://www.hawaii.edu/uhelp/elderlaw.htm)
  - "Deciding What Matters and What to Do", [www.hawaii.edu/uhelp/handbook.htm](http://www.hawaii.edu/uhelp/handbook.htm)
- Refer to elder law attorney as needed
  - Hawaii State Bar Association Lawyer Referral & Information Service, [www.hawaiilawyerreferral.com](http://www.hawaiilawyerreferral.com)
  - University of Hawaii Elder Law Program, [www.hawaii.edu/uhelp/](http://www.hawaii.edu/uhelp/)
  - Legal Aid Society of Hawaii, [www.legalaidhawaii.org](http://www.legalaidhawaii.org)
- Consumer Credit Counseling Services of Hawaii, [www.cccsofhawaii.org/](http://www.cccsofhawaii.org/)
- Guardianship Pro-se Packet, Steps to establish guardianship of an incapacitated person, <https://www.courts.state.hi.us/docs/1FP/ProSelncap.pdf>
- Mediation Services - Mediation Center of the Pacific, 245 N. Kukui St. Ste 206, Honolulu 96817, (808) 521-6767, [www.mediatehawaii.org](http://www.mediatehawaii.org)
- Affordable Lawyers Project, (808) 527-8027

### Preventing Elder Abuse, Neglect and Fraud

- Monitor for Elder Abuse, Neglect and Fraud. If suspected, contact Adult Protective Services, [www.humanservices.hawaii.gov/ssd/home/adult-services/](http://www.humanservices.hawaii.gov/ssd/home/adult-services/)
- Elder Abuse Justice Unit, Office of the Prosecuting Attorney, Honolulu, (808) 768-6452, <https://honoluluprosecutor.org/elder-abuse-justice-unit/>; Hawaii County, (808) 934-3461; Maui County, (808) 270-7777; Kauai County, (808) 241-1888

# Roadmap for Family Caregivers

## DEMENTIA RESOURCES - Continued

### Safety (cont'd)

#### **Preventing Elder Abuse, Neglect and Fraud (cont'd)**

- Hawaii's Fraud Prevention & Resource Guide, [www.cca.hawaii.gov/blog/news-release-hawaiis-fraud-prevention-resource-guide-gets-an-update/](http://www.cca.hawaii.gov/blog/news-release-hawaiis-fraud-prevention-resource-guide-gets-an-update/)
- Information about Medicare/Medicaid Fraud, Contact Senior Medicare patrol (SMP), 1-800-296-9422, [www.smphawaii.org](http://www.smphawaii.org)
- Federal Hotline on Medicare, Medicaid or health care fraud- Inspector General's Office, 1-800-447-8477
- Office of Health Care Assurance, Hawaii Department of Health, <https://health.hawaii.gov/ohca/state-licensing-section/>
- Care Home Complaints, 601 Kamokila Blvd. #361, Kapolei, 96707, (808) 692-7400, <https://health.hawaii.gov/ohca/state-licensing-section/>
- Hospital and Nursing Home Complaints, 601 Kamokila Blvd. #395, Kapolei, 96707, (808) 692-7420, <https://health.hawaii.gov/ohca/state-licensing-section/>
- Long-Term Care Ombudsman, (808) 586-7268, for complaints by or on behalf of residents in long-term care facilities

### Advance Care Planning

#### **Hawaii Advance Care Planning and POLST Forms:**

- Refer to advance care planning facilitator within system, if available
- Encourage, as appropriate, execution of advance health care directive and POLST forms
- Refer to Your Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia, <https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf>
- University of Hawaii Elder Law Program, 2515 Dole St. #201 Honolulu 96822, (808) 956-6544, [www.hawaii.edu/uhelp](http://www.hawaii.edu/uhelp)
- Kokua Mau - Hawaii Hospice & Palliative Care Organization, (808) 585-9977, [www.kokuamau.org](http://www.kokuamau.org)



# Roadmap for Family Caregivers

## DEMENTIA RESOURCES - Continued

### Other Dementia Resources

- Hawaii Alzheimer's Disease Initiative (HADI), [www.hawaii.edu/aging/hadi](http://www.hawaii.edu/aging/hadi)
- Dementia Friends Hawaii, [www.agefriendlyhonolulu.com/dementia-friends/](http://www.agefriendlyhonolulu.com/dementia-friends/)
- Dementia Friends USA, <https://dementiafriendsusa.org>
- Dementia Friends Japan, <https://www.alz.co.uk/dementia-friendly-communities/japan>

### **Hawaii COVID-19 Resources**

- Covid-19 Tips for Caregivers, 1-800-272-3900, [www.alz.org/hawaii/](http://www.alz.org/hawaii/)
- Hawaii Aging and Disability Resource Center COVID-19643-ADRC (2372), [www.Hawaiiadrc.org](http://www.Hawaiiadrc.org)
- Kokua Mau: A Movement to Improve Care, <https://kokuamau.org/covid-19-resources/>
- Healthcare Association of Hawaii Covid-19 Resource Page, 707 Richards St #PH2, Honolulu 96813 (808) 521-8961, [www.hah.org](http://www.hah.org)
- Hawaii Public Health Institute, 850 Richards St #210, Honolulu 96813, (808) 591-6508, [www.hiphi.org/covid19/](http://www.hiphi.org/covid19/)

### **National COVID-19 Resources and Links**

- National Alzheimer's and Dementia Resource Center (NADRC), <http://nadrc.acl.gov>
- The National Alzheimer's Project Act Home Page, <https://aspe.hhs.gov/national-alzheimers-project-act>
- University of California San Francisco COVID-19 Memory and Aging Center, <https://memory.ucsf.edu/covid>
- Administration for Community Living (ACL), <https://acl.gov/COVID-19>
- Centers for Disease Control and Prevention (CDC) Covid-19 page, <https://www.cdc.gov>
- National Alliance for Caregiving Covid-19 Resources For Families, <https://www.caregiving.org/resources/covid-19-resources-for-families/>
- Caregiving In The U.S. 2020 Report, <https://www.caregiving.org/caregiving-in-the-us-2020/>
- Mindset Centre For Living With Dementia, [www.mindsetmemory.com](http://www.mindsetmemory.com)
- Reducing the Stigma of Dementia: The Conversation on How to Talk About Dementia Appropriately, <https://www.dementia.org.au/sites/default/files/resources/dementia-language-guidelines.pdf>

### **International COVID-19 Resources and Links**

- Alzheimer's Disease International, The Global Voice on Dementia, <https://www.alz.co.uk/news/adi-releases-position-paper-on-covid-19-and-dementia>
- Dementia Alliance International COVID-19 Resource Page, <https://www.dementiaallianceinternational.org/covid-19-resources/>

### COVID-19 and Dementia Resources

\*\* If the business is not listed in the Department of Health, check for their business registration in the Hawaii Department of Commerce and Consumer Affairs (DCCA). You can also see if any complaints were filed against the company or individual: <https://cca.hawaii.gov/>



# Roadmap for Family Caregivers

## HELPFUL TIPS

NORMAL AGING	SERIOUS MEMORY PROBLEM (like Alzheimer's)
Making a bad decision once in a while	Making poor judgments and decisions a lot of the time
Missing a monthly payment	Problems taking care of monthly bills
Forgetting which day it is but remembering it later	Losing track of the date or time of the year
Sometimes forgetting which word to use	Trouble having a conversation
Misplacing things from time to time and retracing steps to find them	Misplacing things and losing the ability to retrace steps

NIH National Institute on Aging (<https://www.nia.nih.gov/health/do-memory-problems-always-mean-alzheimers-disease>)

### Some do's and don'ts for effective communication with persons with dementia

DO	DON'T
<ul style="list-style-type: none"><li>• Do use their first name to get their attention</li><li>• Do speak in a normal tone of voice at a normal volume</li><li>• Do your best to eliminate any distractions such as a TV or radio</li><li>• Do give short, one sentence explanations</li><li>• Speak slowly and clearly</li><li>• Allow plenty of time for comprehension</li><li>• Agree with them or distract them to a different subject or activity</li><li>• Accept the blame when something's wrong (even if it's a fantasy)</li><li>• Do encourage reminiscing if it is enjoyable to the person</li><li>• Respond to the feelings rather than the words</li><li>• Be patient, cheerful, and reassuring</li><li>• Go with the flow</li></ul>	<ul style="list-style-type: none"><li>• Don't interrupt</li><li>• Don't reason</li><li>• Don't argue</li><li>• Don't confront</li><li>• Don't question recent memory</li><li>• Don't insist, try again later</li><li>• Don't criticize or correct</li><li>• Don't take it personally</li></ul>



# Roadmap for Family Caregivers

## MCI & STAGES OF ALZHEIMER'S DISEASE

**Symptoms and Duration:** Alzheimer's symptoms vary. The information below provides a general idea of how abilities change during the course of the disease. Not everyone will experience the same symptoms nor progress at the same rate. Find additional information on the stages of Alzheimer's at: <https://www.alz.org/alzheimers-dementia/stages>

### Mild Cognitive Impairment (MCI)

<https://www.mayoclinic.org/diseases-conditions/mild-cognitive-impairment/symptoms-causes/syc-20354578>

- Mild forgetfulness
- Increasingly overwhelmed by making decisions, planning steps to accomplish a task or interpreting instructions
- Mild difficulty finding way in unfamiliar environments
- Mild impulsivity and/or difficulty with judgment
- Family and friends notice some or all of these symptoms
- IADLs\* only mildly compromised; ADLs\* are intact

### Alzheimer's Disease Early Stage

2-4 years in duration

- Increased short-term memory loss
- Difficulty keeping track of appointments
- Trouble with time/sequence relationships
- More mental energy needed to process information
- Trouble multi-tasking
- May write reminders, but lose them
- Mild mood and/or personality changes
- Increased preference for familiar things
- IADLs more clearly impaired; ADLs slightly impaired

### Alzheimer's Disease Middle Stage

2-10 years in duration

- Significant short-term memory loss; long-term memory begins to decline
- Fluctuating disorientation
- Diminished insight
- Changes in appearance
- Learning new things becomes very difficult
- Restricted interest in activities
- Declining recognition of acquaintances, relatives
- Mood and behavioral changes
- Alterations in sleep and appetite
- Wandering
- Loss of bladder control
- IADLs and ADLs broadly impaired

### Alzheimer's Disease Late Stage

1-3 years in duration

- Severe disorientation to time and place
- No short-term memory
- Long-term memory fragments
- Loss of speech
- Difficulty walking
- Loss of bladder/bowel control
- No longer recognizes family members
- Inability to survive without total care

\*IADLs (Instrumental Activities of Daily Living) are activities that allow people to live independently such as shopping, preparing food, housekeeping, managing finances

\*ADLs (Activities of Daily Living) are activities for self-care such as feeding, toileting, dressing, bathing

# Roadmap for Family Caregivers

## MIND DIET

### Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet

The MIND diet is a combination of the Mediterranean and Dietary Approaches to Stop Hypertension (DASH) diets. It aims to reduce the risk of developing dementia and improve brain health. Please consult with your physician first.

### The MIND Diet - 9 Foods to Eat

FOOD	QUANTITY & SERVINGS	EXAMPLES & TIPS
<b>Green Leafy Vegetables</b>	At least 1 serving/day *One serving = 1 cup raw or ½ cup cooked	Spinach, kale, collards, Swiss chard, mustard greens, turnip greens, dandelion greens, arugula, endive, grape leaves, romaine lettuce
<b>Most Other Vegetables</b>	At least 1 serving/day *One serving = ½ cup	<b>*A salad + at least 1 other veggie everyday</b> Asparagus, broccoli, brussels sprouts, cabbage, carrots, cauliflower, eggplant, green beans, mushrooms, onions, okra, snow peas, squash, bell peppers, sweet potatoes, tomatoes/tomato sauce
<b>Nuts</b>	5 oz. total/week *One serving = 1 oz.	Peanuts, almonds, walnuts, cashews, pistachios, or Nut butter
<b>Berries</b>	At least 5 servings/week *One serving = ½ cup	Blueberries, strawberries, raspberries, blackberries
<b>Beans/Legumes</b>	At least 3 servings/week *One serving = ½ cup	Black, pinto, cannellini, garbanzo, kidney, lima, red/white, navy, lentils, tofu, edamame, hummus, soy yogurt
<b>Whole Grains</b>	3 servings/day, every day *One serving = ½ cup or 1 slice	Dark or whole grain bread, brown rice, whole grain pasta, wild rice, quinoa, barley, bulgur, farro, oats, whole grain cereal
<b>Fish</b>	At least 1 serving/week *One serving = 3 to 5 oz.	<b>*Not Fried</b> Salmon, tuna, tilapia, cod, mahi mahi, halibut
<b>Poultry</b>	At least 2 servings/week *One serving = 3 to 5 oz.	<b>*White meat &amp; Skinless</b> Chicken or turkey breast
<b>Extra Virgin Olive Oil</b>	2 TB/day *One serving = 2 TB	<b>Use EVOO as primary oil</b> <b>Look for Unrefined EVOO</b>

### The MIND Diet - 5 Foods to Avoid

FOOD	QUANTITY & SERVINGS	EXAMPLES & TIPS
<b>Red Meat &amp; Processed Meat</b>	No more than 3 servings/week *One serving = 3 to 5 oz.	Beef, lamb, pork, ham, burger, hot dogs, sausages, bacon, roast beef, salami
<b>Butter &amp; Stick Margarine</b>	Less than 1 pat (tsp)/day	<b>*Use EVOO instead</b> <b>*Smart Balance, Earth Balance</b>
<b>Regular Cheese</b>	No more than 2 oz./week	Full fat cheeses
<b>Pastries &amp; Other Sweets</b>	No more than 4 treats/week	Biscuit/roll, pop tarts, cake, snack cakes/Twinkies, Danish/sweet rolls/pastry, donuts, cookies, brownies, pie, candy bars, other candy, ice cream, pudding, milkshakes
<b>Fried Foods &amp; Fast Foods</b>	No more than 1 meal/week	Fast food or Fast casual restaurants Any fried foods including fried potato chips

Adapted: Morris, MC et al. MIND diet associated with reduced incidence of Alzheimer's disease. *Alzheimer's & Dementia*; 2015. Lindseth, G. et al., *Neurobehavioral Effects of Consuming Dietary Fatty Acids*. Biol Res Nurs 2016 Jul 13.



# 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.



### 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.**

### 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.



### 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.



### TAKE CARE OF YOUR MENTAL HEALTH

Some studies link depression with cognitive decline, so seek treatment if you have depression, anxiety or stress.



### CATCH SOME ZZZ'S

Not getting enough sleep may result in problems with memory and thinking.



### FUEL UP RIGHT

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



[https://www.alz.org/help-support/brain\\_health/10\\_ways\\_to\\_love\\_your\\_brain](https://www.alz.org/help-support/brain_health/10_ways_to_love_your_brain)

alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS®



*To care for those who once cared for us is one of the highest honors.*

*- Tia Walker*

# *Mahalo* for all you do



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