Supported in part by a cooperative agreement No. 90AL0011-01-00 and 90ADSG0003-01-00 from the Administration on Aging, Administration for Community Living, U.S. Department of Health and Human Services. Grantees carrying out projects under government sponsorship are encouraged to express freely their findings and conclusions. Therefore, points of view or opinions do not necessarily represent official AoA, ACL, or DHHS policy. The grant was awarded to University of Hawaii Center on Aging for the Alzheimer’s Disease Initiative: Specialized Supportive Services Program and the Executive Office on Aging for the Alzheimer’s Disease Supportive Services Program.

This training series is based upon the Dementia Capability Training Series developed by Terry Barclay, PhD and Michelle Barclay, MA and funded by the Minnesota Board on Aging, grant number 90AL0007-01-00 from the U.S. Administration on Aging, U.S Department of Health and Human Services, Administration for Community Living.
Overall Training Objectives

- Understand the basics of Alzheimer’s disease and related dementias
- Identify people with possible dementia and/or their care partners during the screening and assessment process, and
- Connect them to resources they need via warm handoff within the No Wrong Door system
Part III: Strategies to Support Families Living with Dementia in the Community
Key Strategies

- Identify Problems, Challenges & Needs
  - Assessment

- Provide Emotional Support
  - Listening, validating, empowering without judgment or criticism

- Connect to Resources & Services
  - One-Stop Shop
  - “Warm” Referral
• Adult Day Programs
• Adult Protective Services
• Assistance With Money Management
• Assistance With Shopping, Cooking, Cleaning, Laundry, and Other Household Activities
• Assistance With Taking Medications
• Assisted Living Residences
• Behavioral Symptom Management
• Chore Services
• Financial Support, Benefits Counseling, and Assistance With Applications for Benefits
• Grief Counseling
• Home Modifications
• Hospice
• Housing
• Information and Education About Dementia
• In-Home Skilled Nursing
• Legal Services
• Meals on Wheels
• Mental Health Services
• Nursing Homes

• Occupational Therapy
• Peer Support, Mentoring, and In-Person, Telephone, and Online Discussion Groups for the Person With Dementia
• Personal Care Assistance, Including Help With Bathing, Dressing, Eating, and Toiletting
• Personal Emergency Response Systems
• Physical Exercise
• Physical Therapy
• Professional Counseling for the Person With Dementia and/or the Family Caregiver
• Recreation for the Person With Dementia, the Family Caregiver, or Both
• Respite Services
• Skill-Building Training About Dementia Care for Family and Other Caregivers
• Socialization, Including Formal Social Activities and Opportunities for Informal Socialization
• Speech and Language Therapy
• Support Groups for the Person With Dementia and the Family Caregiver
• Telephone Helplines
Universal Needs

- Care Partners/Team
- Disease Education
- Safety
- Behavioral Symptom Management
- Health, Wellness & Engagement
- Caregiver Support
Identify Care Partner(s)/Team

- Educate: Team approach needed
  - Marathon, not sprint; team sport, not individual

- Identify a support system
  - Think outside the box: Family, friends, neighbors, religious congregation members, colleagues, community organization volunteers or workers
  - Task specific (e.g., doctor visits, grocery shopping, transportation, social activities, etc.)
ASK:
- What they know about the disease / questions about the diagnosis / disease
- Biggest concerns / fears / challenges

FOCUS & CUSTOMIZE:
- Stage-Specific: Don’t get too far ahead
- Information on 1-2 topics
Safety

Plan for the 6 F’s:

- Falls
- Freedom
- Freeways
- Firearms
- Finances
- Fire

Safety Tips: Falls & Freedom

✦ FALLS
  ✅ Fall risk assessment
  ✅ Sensory / mobility aids
  ✅ Home safety inspection / modifications
  ✅ Driving evaluation

✦ FREEDOM
  ✧ Encourage Medic Alert® Safe Return®
    ✧ 6 out of 10 people with dementia will wander at some point during the disease
Safety Tips: Freeways

FREeways

Watch how four families deal with different issues related to dementia and driving.

A Supportive Conversation: Frank has early stage Alzheimer's and the doctor said it's no longer safe for him to drive. His wife doesn't drive, but knows it's time to discuss finding alternative transportation. Full Screen

Alzheimer’s Association Driving Center:
www.alz.org/care/alzheimers-dementia-and-driving.asp

FIREARMS: Best plan is one made before it’s needed

- Store guns unloaded in locked cabinet
  - Store ammo separately in locked, fireproof case
- Gift guns to family or friends
- Friend/Family member “borrows” guns
- Guns being “professionally cleaned”
- Guns are “broken” – professional disables firing mechanism or installs trigger guard
- Sell guns, turn guns over to law enforcement for destruction
Safety Tips: Finances & Fire

- **FINANCES**: Risk of financial abuse
  - Bill paying plan
  - Power of Attorney
  - Worst Case: Stop / reroute mail, no call lists (to avoid solicitation)

- **FIRE**: Ask – What would you do if there was a fire?
  - Stove / oven / cooking safety
  - Alarms / smoke detectors
• Encourage emergency plans
  ➢ Key phone numbers labeled / programmed
  ➢ Fire plan
    • *Ask:* What would you do if there was a fire at your house?
  ➢ ER / Hospital Medical Emergency Kit - @ bedside
    ✓ POLST, POA, Health Care POA, Living Will
    ✓ Updated Medication List + allergy list
    ✓ Slippers / Clothes (including adult diapers, if worn)
    ✓ List of important contact numbers (doctors, family, minister, helpful friends)
    ✓ Comfort objects (music, photos, blanket, etc.)
50%-90% of persons with dementia will develop behavioral symptoms

Anxiety is the most prominent in the earlier stages of dementia

42% become physically aggressive

50% have depressive symptoms

Prevalence of behavior is influenced by the care partner’s approach
Behavior Problems

- Emotion Outburst
- Wandering
- Refuse: Bath Dressing
- Frustrated
- Hallucination
- Delusions: Not my house, daughter
- Hoarding
Causes of Challenging Behaviors

- Physical Health (Medical)
  - Pain
  - Urinary Tract Infection
  - Illness

- Environment
  - Unfamiliar surroundings/environment
  - Over/under stimulation

- Other
  - Communication
  - Unmet needs/boredom
  - Task-related
  - Emotional health
All Behavior is Communication

- **REMEMBER:**
  - behavior is communication
  - communication impacts behavior

- Think like a behavioral analyst
  - Detective work, ask:
    - Who (is involved/present)
    - What (exact description, be specific)
    - When (time dependent? only in morning? triggers?)
    - Where (location specific?)
    - Why (what happens right before, right afterwards? what do family think is cause? Has anything changed recently?)
Prevention Tip:
Strive for Positive Communication

- **Don’t Argue!** Validate, Agree, Distract / Change the Subject
- Be excessively polite. (“Do you have time to help me now?”)
- Apologize. (“I’m sorry to interrupt you.”)
- Don’t take it personally! It’s the disease talking.
- Take a deep breath. Remember, it is you who must change.
- Strive for happy moments.
Health, Wellness & Engagement

Encourage lifestyle changes that may reduce disease symptoms or slow progression

- Exercise
- Nutrition
- Stress reduction
- Meaning & purpose
- Relationships
- Health management
- Routine

www.alz.org/mnnd/documents/15_ALZ_Living_Well_Workbook_We b.pdf
Health, Wellness & Engagement

- Facilitate regular physician appointments
  - Reminders, transportation

- Create medication management plan
  - Medication List & Review (pharmacist / doctor)
  - Family plan for managing meds
  - Med management aids (pill boxes, alarms, medication list)
Maximize Abilities: Routine

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<tr>
<th>MORNING</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
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<td>8:30 a.m. Mediterranean breakfast</td>
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<td>9:30 a.m. Gardening</td>
<td>10 a.m. Water Aerobics</td>
<td>9:30 a.m. Golf with Jim</td>
<td>9:30 a.m. Gardening</td>
<td>10 a.m. Water Aerobics</td>
<td>10 a.m. Brunch with Friends</td>
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<td>12 p.m. Lunch with friends</td>
<td>12 p.m. Lunch</td>
<td>12 p.m. Lunch at the gym</td>
<td>12 p.m. Lunch with Jim</td>
<td>12 p.m. Lunch with friends</td>
<td>12 p.m. Lunch at the gym</td>
<td>12 p.m. Nap</td>
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<td>2 p.m. Card club</td>
<td>2 p.m. Volunteer</td>
<td>2:30 p.m. Nap</td>
<td>2 p.m. Volunteer</td>
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<td>3 p.m. Snack</td>
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<td>6 p.m. Yoga Class</td>
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<td>7:30 p.m. Dinner with Neighbors</td>
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# Appointment Log

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Providing support for dementia care partners is a societal imperative

- 70% of individuals with Alzheimer’s disease live at home
- In 2012, an estimated 15 million unpaid caregivers provided an estimated 17.5 billion hours of unpaid care
- The health care system could not sustain the cost of care without unpaid caregivers
Dementia Caregiving Risks

- **Physical risks:**
  - risk of health problems

- **Social risks:**
  - feelings of social isolation

- **Psychological risks:**
  - risk of depression and burden

- **Financial risks:**
  - financial burden due to lost wages & cost of care
There is a strong correlation between the health and well-being of a care partner and the quality of care that she can provide.

A care partner with a balanced outlook and good self-care practices can provide care for longer periods of time while maintaining his own health and well-being.

Caregivers need: education, planning assistance, other caregivers, time away, emotional support, health & wellness.
Special Challenge: Living Alone

- Published research on the numbers of older Americans with dementia living alone vary (research challenging)
  - Approx. 15-33% (1:7 to 1:3)

- Up to 50% have no one checking on them at least once a week

- 30% or more have no support at all
Population Characteristics

- At greater risk of:
  - Poor self-care
  - Malnutrition
  - Abuse/neglect
  - Accidental self-harm
  - Medication mismanagement
  - Untreated medical conditions
  - Loneliness

- Inactivity
- Immobility
- Financial mismanagement, fraud, scams
- Triggering emergency response from medical, law enforcement, APP
- Accidental death
Living Alone

- Every person with dementia living alone does **NOT** need a guardian.

- **People can live alone safely in the early & middle stages** of the disease, with the right supports
  - **KEY** is good assessment (and re-assessment) + planning, home modifications, technology and connection to community resources and support

- Face-to-face visits important
  - Labor intensive
Initial Steps

- If no diagnosis, first step is to try to facilitate work-up

- If family or care partner involved, identify primary/secondary as point of contact
  - If no CP, try very hard to identify a person who can spend 15+ min of face-to-face time with individual on daily (or at least weekly) basis to monitor
  - Visitation programs

- Care Plan
  - Same objectives, more support
Assistive Technologies

- GPS Wristbands
- Motion-sensitive devices
  - Lighting
  - Care partner voice reminders (“lock the door”, “call your son before going outside”)
- Remote home monitoring devices
  - Motion, weight sensitive floor mats with caregiver alerts
- Automatic medication dispensers
- Dial-free photo-phones
- Low temp burners for stove
  - Can still boil water but reduces risk of fire
- Overhead automatic fire extinguisher (above stove)
- Anti-scald faucet nozzle
- Faucet timers
Legal & Financial Planning

• Encourage patient / care partner to assign durable POA
  ✓ Refer to Elder law attorney

• Encourage patient / care partners to talk about long-term care and when they would access support
  ✓ http://www.alz.org/i-have-alz/downloads/worksheet_financial_legal.pdf
Advance Care Planning

• Encourage patient to discuss / document preferences for care in a health care directive
  ✓ Honoring Choices
  ✓ MN Healthcare Directive
  ✓ POLST

• Discuss palliative and hospice options
  ✓ Palliative Care Consultation Program
  ✓ When is the right time?
Connect to Resources

Alzheimer’s Association
24/7 Helpline | 800.272.3900
www.alz.org/hawaii

Hawaii Aging & Disability Resource Center (ADRC)
643-ADRC (2372) | TTY line: 643-0889
www.hawaiiadrc.org
Alzheimer’s Association
Aloha Chapter
Available on Oahu, Kauai, Maui, Island of Hawaii

- Multilingual information
- Care consultation
- Education for caregivers
- Community and professionals
- Support groups
- Safety programs, such as MedicAlert® + Alzheimer’s Association Safe Return®
- A clinical trials index: TrialMatch®
- Online training and dementia certification
Public Health Nurses (PHN) are Registered Nurses (RN) found in every community across the state. PHNs help the elderly manage their care through case management services in order to remain safely in their home for as long as possible.

Memory Care Navigation services include:

- Administration of dementia screening tool such as Mini-Cog
- Support client with memory concerns/dementia and their caregiver in navigating the health care system
PHN Referral Form

State of Hawaii
Health Department

REQUEST FOR NURSING SERVICES

DATE:

CLIENT:

SEX: BD: / / School / Gr:

Last
First

SEX: BD: / / School / Gr:

SEX: BD: / / School / Gr:

ADDRESS: APT. NO HOME PHONE:

Mailing address (if different):

FATHER:

Last
First

SEX: BD: / / Phone:

work

Mother:

Last
First

SEX: BD: / / Phone:

work

Other Contact Person / Phone:

MEDICAL INSURANCE & NUMBER:

PHYSICIAN / PCP:

Medical / Clinical Diagnosis:

REASON(S) FOR REFERRAL:

SIGNIFICANT INFORMATION:

PLANNED DISCHARGE DATE:

HOSPITAL:

OTHER AGENCIES INVOLVED OR REFERRED TO:

CONTACT PERSON & PHONE NUMBER:

REQUESTED BY:

Title: Agency:

ADDRESS:

PHONE:

PHN SUMMARY:

For PHN Office Use Only:

Date Rcv’d: ____________________________ CT Assigned PHN: ____________________________

Currently Carried □ No □ Yes By: ____________________________ Previously Carried by: ____________________________

QA: ____________________________ Live: ____________________________

DISPOSITION: □ Admitted □ Disposition Letter Sent; Date: ____________________________ Not admitted date: ____________________________

Left Uncovered □ R Refused PHN service □ C Assistance from Other Agency / Program: ____________________________

HOME HEALTH

- Home health agencies provide *physician ordered* short term rehabilitation services to seniors at home
- Eligible – homebound
- Cost – Covered by all medical insurances
- Services – Skilled nursing eg. Wound care
  - Physical therapy  including home safety evaluation
  - Occupational therapy
  - Speech therapy
  - Social work
  - Home health aide
Hospice provides comfort care and support for seniors with advanced dementia

Cost – Covered by all medical insurances

Services – Interdisciplinary team (RN, SW, chaplain, HHA, MD) come to the home

Criteria for Advanced Dementia
- Speech limited
- Ambulatory ability lost
- Inability to maintain weight
- Recent hospitalization or ER visit
- Pressure ulcers
- Infections – UTI, pneumonia, sepsis etc.
Kupuna Care

- Service Providers on Hilo, Kona, Oahu, Kauai, Maui

- Services
  - Case Management
  - Adult day care
  - Chore and Homemaker
  - Attendant care
  - Home delivered meals
  - Transportation
  - Personal care eg. bathing

- Eligibility
  - > 60 years of age
  - Living at home
  - Problems with 2 or more ADLS
Medicaid

- Quest Integration – Aged Blind and Disabled
- Managed Care Organizations – United Healthcare, Ohana, Alohacare, HMSA, Kaiser
- **Home and Community Based Services**
  - PA 1 and PA 2
  - Foster Home
  - Home delivered meals
  - Private duty nursing
  - Transportation
  - Adult day care and day health
  - PERS
Veterans

- VA Health benefits eligibility – active military service for 24 months or more with honorable discharge

- Services – Home Health
  - Hospice with room and board coverage
  - Foster Home
  - Respite
  - Home based primary care (interdisciplinary team)
  - Caregiver support
  - Private duty nursing
  - Adult Day care or Day Health
  - Housing (homeless vets)
Summary of Process

CARE COORDINATION PRACTICE TOOL

COGNITIVE IMPAIRMENT IDENTIFICATION AND DEMENTIA CARE COORDINATION

PATIENT

- Mini-Cog score 0-1 or Family Questionnaire 3 or more
- Assess using SLUMS or MoCA
- Score falls outside of normal range

Diagnosis

DEMENTIA CARE COORDINATION

- Identify care partner
- Conduct comprehensive assessment of patient
- Provide disease education
- Develop care plan based on patient’s diagnosis and stage of disease (MCI, early, middle, late), needs and goals
- Arrange services and supports
- Determine visit frequency
- Develop plan for communication
- Monitor patient for changes in condition, medication management needs and emergency room or hospital admission
- Re-evaluate and modify care plan as needed

* The basis CDA M manual uses the term “Mild Neurocognitive Disorder” for dementia and “Mild Neurocognitive Disorder” for mild cognitive impairment. The ACT on Alzheimer’s resource uses the more familiar terminology, as the new term has not yet to be universally adopted.
Summary of Process

Person/Client comes through “Door”

AD8 and/or Mini-Cog

Referral to PCP
If on Medicaid, refer back to Service Coordinator
Electronic Referral Tool to Refer to ADRCs for LTSS
Connect to Community Resources

If on Medicaid, refer back to Service Coordinator
Don’t forget

- Please turn in your evaluation
- CEU available for SW
- Jody Mishan Contact
  - Cell 808-295-2624
  - Email jmishan@hawaii.rr.com