

August 12, 2015

Geriatric-Competent Care: Caring for Individuals with Alzheimer's Disease

Next Steps after Diagnosis: Preparing the Patient/Client and their Caregivers



Next Steps after Diagnosis of Alzheimer's Disease

- **Developed by:**

- The American Geriatrics Society
- Community Catalyst
- The Lewin Group

- **Hosted by:**

- The Medicare-Medicaid Coordination Office (MMCO) Resources for Integrated Care

<https://www.resourcesforintegratedcare.com/>

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Support Statement

This webinar is supported through the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) to ensure beneficiaries enrolled in Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to Medicare-Medicaid enrollees, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar series.

To learn more about current efforts and resources, visit Resources for Integrated Care at:

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- Planning Committee:
 - Gregg Warshaw, MD
 - Nancy Wilson, MSW

- Faculty:
 - Rob Schreiber, MD, CMD
 - Lisa P. Gwyther, MSW, LCSW
 - Debra L. Cherry, PhD

Introductions

- **Robert Schreiber, MD, CMD**, Medical Director of Evidence-based Programs; Hebrew SeniorLife Department of Medicine; Medical Director of the Healthy Living Center of Excellence; Clinical Instructor of Medicine, Harvard Medical School
- **Lisa Gwyther, MSW, LCSW**, Associate Professor, Department of Psychiatry and Director, Alzheimer's Family Support Program, Center for the Study of Aging and Human Development, Duke University
- **Debra L. Cherry, PhD**, Executive Vice President, Alzheimer's Association California Southland, Los Angeles



Webinar Outline/Agenda

- Audience Poll on Workplace and Professional Discipline
- Preparing the Patient and Caregivers
- Working with Families after Diagnosis
- The Dementia Cal MediConnect Project
- Q&A
- Evaluation Survey
- Post-test (for CME/CE Applicants)

Webinar Learning Objectives

- Upon completion of this webinar, participants will be able to:
 - Identify common reactions to a diagnosis of dementia and relevant actions needed over the course of the illness.
 - Be prepared to assess family needs and provide guidance around the varying roles families may perform as caregivers: care coordinator, direct care provider, and long-distance support.
 - Display knowledge of teamwork and strategies needed to help patients and families of different backgrounds access valuable home and community-based resources.

Preparing the Patient and Caregivers

Rob Schreiber MD, CMD



Overview

- Confirm the Diagnosis
- Identify the Stage
- Goals and Values
- Education
- Medication
- Ongoing Support

Confirm the Diagnosis

- Is it Alzheimer's Disease?
- What does this mean to the person/family?
- Do they understand the diagnosis?
- Have they had education about dementia and an understanding of the course of the disease?

Stages of Alzheimer's Disease (I)

Early Stage

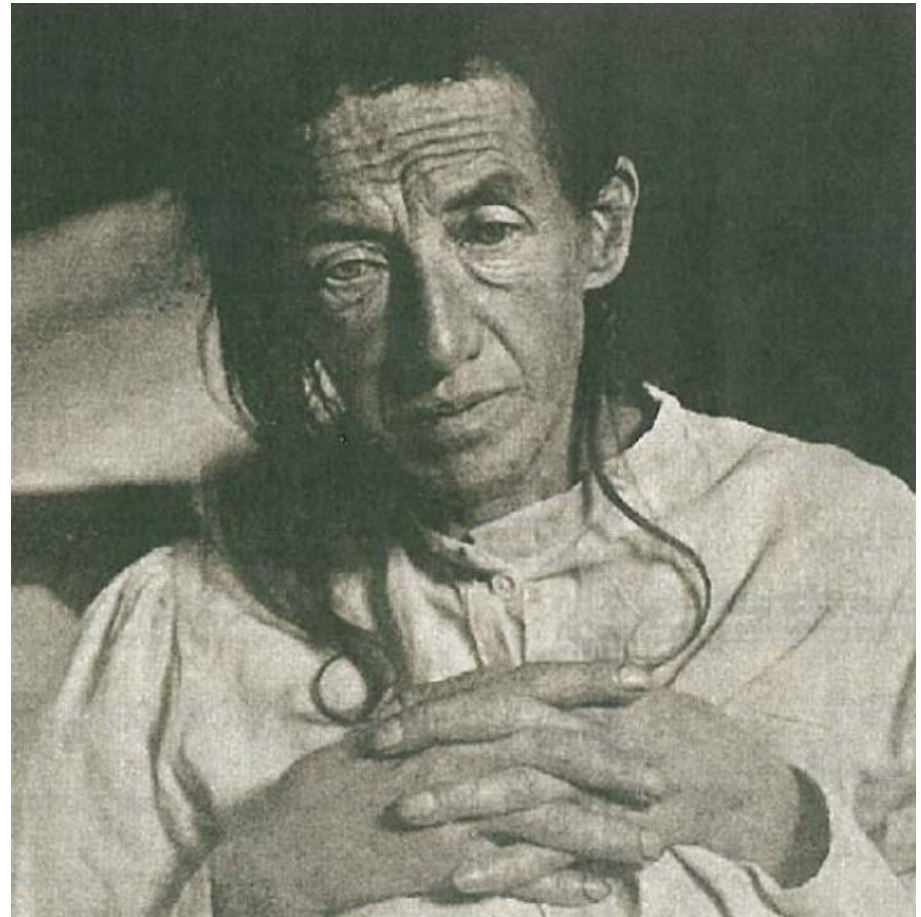
- Anterograde amnesia with rapid rate of forgetting
- Changes in executive function, impaired judgment, or problem solving ability
- Intrusion errors and anomina
- Visuospatial difficulties
- Mood disorder

Middle Stage

- Progressive Memory Loss
- Fluent aphasia with circumlocutions, semantic paraphasias, and impaired comprehension
- Progression of executive dysfunction and visuospatial difficulties
- Apraxia
- Agnosia
- Behavioral problems
- Functional decline

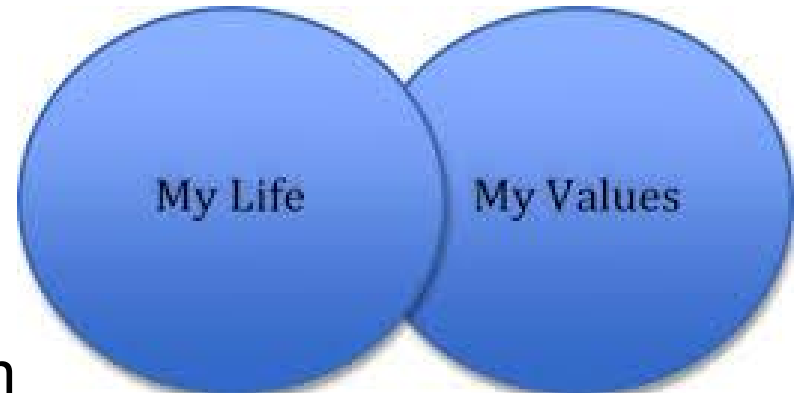
Stages of Alzheimer's Disease (II)

- Late Stage
 - Memory severely compromised
 - Severe functional impairment
 - loss of activities of daily living (ADLs)
 - Speech limited with echolalia
 - Bradykinesia, rigidity, gait disorder
 - Behavioral disturbances



Goals of Treatment

- What matters most to the individual and family?
- Focus on quality of life and function
- Education
- Maintain and, if possible, improve cognition
- Manage comorbidities
- Behaviors
- Work with interdisciplinary team



Education of Family and Caregiver

- Often lacking
- Standardized approach
 - Who does it?
 - What is covered?
- PCP needs to work collaboratively with interdisciplinary team (IDT) with expertise
 - Social worker, Nursing
 - Virtual Consult with social worker at the Alzheimer's Association
- Ongoing support network

Two Types of Medication (I)

- **Acetylcholinesterase inhibitors (AChEIs)**
 - Donepezil
 - Galantamine
 - Rivastigmine
- **Glutamate pathway modifiers**
(memantine hydrochloride)

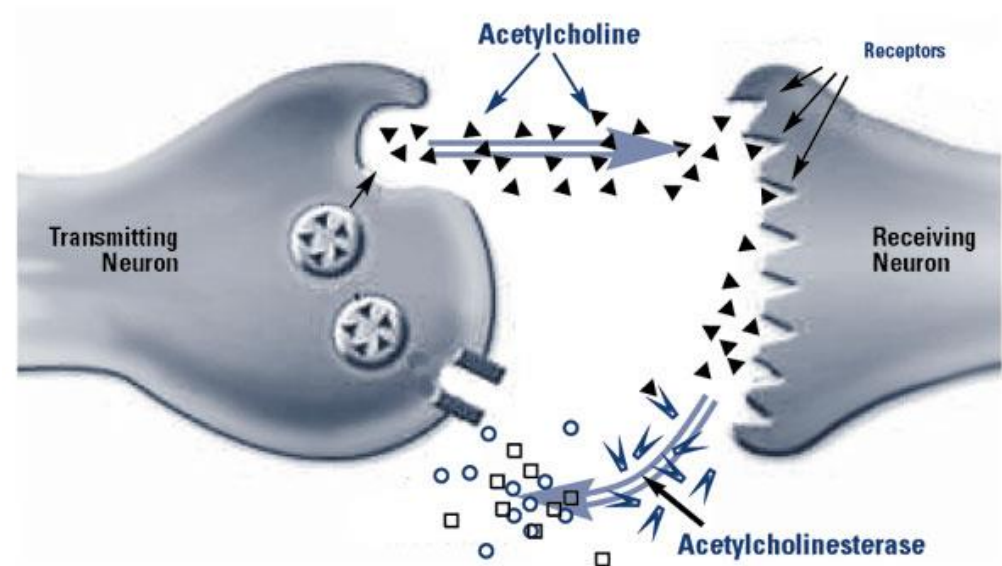
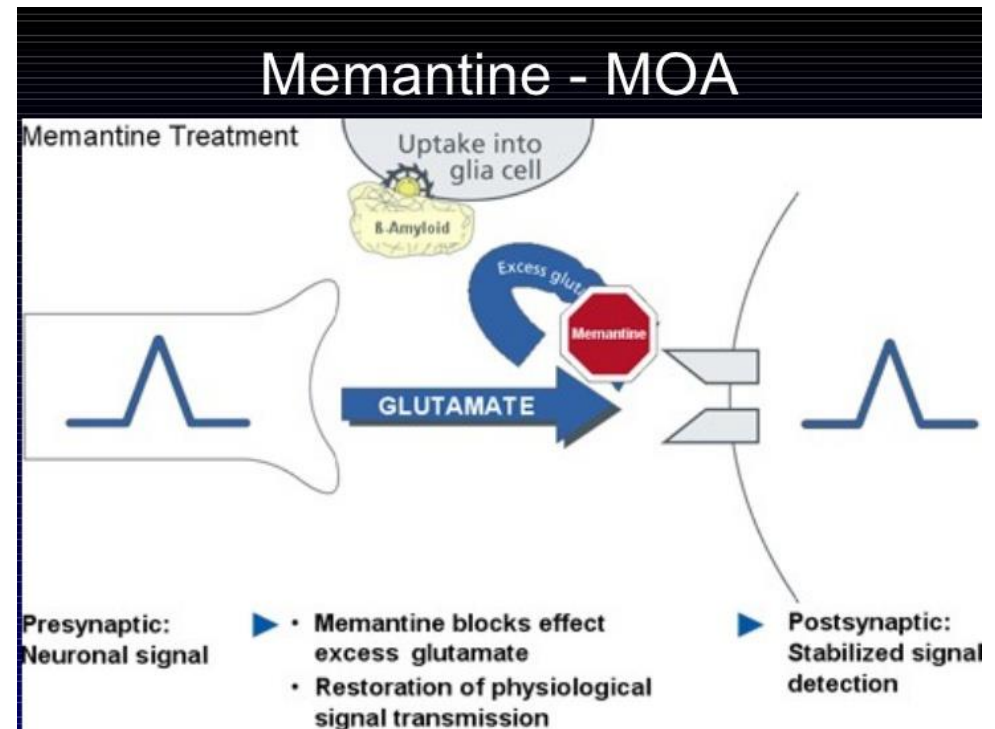


Fig. 1. After signalling, acetylcholine is released from receptors and broken down by acetylcholinesterase to be recycled in a continuous process.

Two Types of Medication (II)

- **Glutamate pathway modifiers**
(memantine hydrochloride)



Medication Impact

- No evidence that medication slows the underlying disease process in patients with Alzheimer's disease
- Some evidence that 1/3 of patients see some benefit with functional improvement and/or behavior changes

Healthy Behaviors to be Emphasized by PCP

- Control of chronic disease(s)
- Physical activity
- Nutrition
- Mental stimulation
- Mood
- Sense of purpose
- Socialization
- Sleep hygiene

Caregivers: Critical Role

- Dementia caregiving is associated with high emotional strain, poor physical health outcomes, and increased mortality

- Primary care providers should ***routinely identify Medicare beneficiaries who are family caregivers*** as part of the Health Risk Assessment in Medicare's annual wellness visit
 - Track the beneficiary's health status and potential risks from caregiving, including physical strain, emotional stress, and depression

 - Monitor their health status with visits involving their loved one

PCP Collaboration with Community Based Organizations

- Critically important roles
- Long Term Services and Supports provided by Area Agency on Aging
 - National Association of Agencies on Aging
202.872.0888 <http://www.n4a.org/>
 - Home supervision, Adult Day Care, Meals on Wheels, transportation, care management, and monitoring
 - Caregiver support, environmental support
- Money follows the person

Ongoing Support of the Patient and Caregiver/Family

- Support groups
- Educational program
 - Coping with Memory Loss
 - Caregiver Support Series
 - Evidence based Programs
 - Powerful Tools for Caregivers
- 24/7 hour hotline Alzheimer's Association 1.800.272.3900
<http://www.alz.org/>
- IDT counseling for alternative housing arrangements as disease progresses

Ongoing Management

- Regular visits
- Social support by IDT
- Sleep issues
- Caregiver check in
- Identify goals of care and update
- Prevention of adverse drug reaction
 - Over the counter medications
 - Other medications with anticholinergic impact including allergy meds, anxiolytics, antidepressants, urinary frequency meds
- Hospitalization avoidance
- Access to urgent care and Emergency Department avoidance

Treatment of Behaviors

- In early stages, behavior and personality changes
 - Irritability, Anxiety, Depression
- In later stages, other symptoms may occur
 - Anger, Agitation, Aggression
 - General emotional distress
 - Physical or verbal outbursts
 - Restlessness, pacing
 - Hallucinations
 - Sleep disorders
- Behaviors will occur in almost all cases and there are treatments

Summary

- PCP collaboration with interdisciplinary team
- Understand the individual's values and goals
- Education, healthy behaviors, and community supports are critical components to effective treatment
- Medications will not change the disease trajectory
- Behaviors should be expected and plan for treatment
- Caregiver support is essential

Working with Families After Diagnosis

Lisa P. Gwyther, MSW, LCSW



More than Memory

*“I want to be treated just like normal.
Alzheimer’s isn’t my whole life. Am I a case?
I thought I was just one of the Ramblers...”*

Radio interview, Tommy Thompson
NC Red Clay Ramblers Musician

We Do Wonder

“I get tired of asking when and what is going to happen, but I don’t want to keep my mouth shut all the time. I want to be part of something. We people with Alzheimer’s actually do wonder how things happen and why. We want things to be like they used to be – it hurts like hell”.

Cary S. Henderson, PhD
Partial View (1998)

What Do Families Say?

- There is never enough of me or enough of the quality affordable help I need.
- People tell me to take care of myself – yeah, right!
- I'm losing “me” and “us” – I miss having him in control.
- I need a “Charlie app.”
- I'm proud to be her caregiver, but it's something I do, not who I am.
- We Southerners pass down guilt and regret like pound cake recipes and broaches.

Family Care Happens

- It's just a question of when and for how many
- Family care affects all relationships
- Family care is rarely fair or equal
- Many families see no choice
- Family care disrupts lives

What Can Families Expect?

- Organizing daily and adapting work schedules
- Finding, asking for, and using new help
- Solving new problems
- Making, carrying out, and living with the consequences of decisions
- Dealing with relationship changes, imbalances in family give-and-take
- Dealing with resentment, disappointed expectations, and uncertainty

What Must Families Do?

- Define and negotiate complex, changing situations
- Perform physically intimate and/or medically complex tasks
- Manage emotions, behavioral changes, and communication
- Modify expectations
- Capitalize on preserved capacities

Dementia Family Care: Balancing Autonomy

- Whose needs?
- Competing loyalties and commitments?
- How long?
- How much?
- How to evaluate risk, cost, and benefit?

Decision Points in Post-Diagnosis Dementia Care

- Changes in handling money, alcohol, driving, travel, meds
- Changes in safety – fraud, neglect, wandering, falls, exploitation, live-alones
- Navigating HIPAA and Health/Services systems
- Resistance to change, services, moves
- Illness, injury, change in caregiver

Preparing Families for Tough Decisions

- New problems aren't necessarily related to what you do or don't do. The person is unhappy because s/he is living with unwanted dependency.
- It's easy to second guess or criticize from a distance.
- Doubts are inevitable, but doing nothing is risky
- Choices, options and lives are different from what they were. It's impossible to know what s/he would have done if your positions were reversed.
- People with dementia often take out frustration on close family

Decision-Making Hazards

- Unrelenting serial crises
- Old promises
- Chasing ghosts
- Conflicting perceptions, expectations
- Control issues
- Too few good choices

Early Stage Families Need Explanations

- He's not himself – lost interest, initiative, short fuse, will never go anywhere
- She reads my reminders but doesn't follow them
- He goes to the bank every day, but he doesn't pay bills or taxes. The neighbors, banker & pharmacy are complaining
- It took her an hour to get to the beauty shop on the corner
- He messes up minor repairs, but he won't let us help – it's costly

Moderate Dementia: Prepare Families for Changes

- Rejection of help: I showered this morning
- Perseveration: Kleenex, Vitamins, checking and searching
- Shadowing
- Disinhibition: Public vs. private behavior, eating only sweets
- Misidentifications: Not my real husband
- Confabulation (not lies)
- Delusions: suspicious, theft, infidelity
- Visuospatial changes: falls, balance

Safety and Alzheimer's Disease

- Financial protections – paid stranger \$1700 for gutters
- Driving
- Medication management, OTCs, toxins
- Guns, power tools, kitchen, bathroom
- Safe Return/Medic Alert/ Silver Alert
- Monitoring: Low and high tech

Home Alone: “She Fired the Help”

- Telephone? Mail?
- Med management?
- Day/Night?
- Travel outside home?
- Bathroom/ continence?
- Falls/ injuries? Kitchen risks?
- Weight loss/ food management
- Available discreet surveillance?

Family Resistance to Community Help

- Stigma & Urban Legends
- Cost/ Preserving assets or saving for rainy day
- Denial/ Poor judgment
- Too many changes at once
- Loss of control
- Overwhelming disclosure in assessment – privacy issues

How Care Managers Can Help

- Family and person-centered information, assessment and plan – update as goals, priorities change
- Decisional support and acknowledgement
- Reminders re: imperfection, uncertainty
- Help with feelings: failure, loss of control, guilt, regret, grief, depression, anxiety, anger
- Fresh perspective, appraisal of options, adaptation or coping tips, skills-based problem solving, and self care strategies

What Families Need and Prefer

- Reliable, current and trusted continuing source of information
- Help with symptom management (Alzheimer's Medical Advisor in testing)
- Help navigating health/social service system
- Criteria for evaluating quality/cost/benefit of services

Families Ask Care Managers

- Why does she say we never visit but we do?
- How can she be so nice to strangers and so mean to us?
- I've never lied to my mother, but the truth isn't working....
- I can't NOT take it personally – We never fought like this.
- Why couldn't she remember the good stuff?
- How long will it be until....?

Evidence-Informed Family Interventions

- Treat depression/anxiety
- Increase pleasant events
- Psychoeducation/skills training/Healthy Ideas
- Problem solving skills
- Exercise/Mindfulness/Stress Management/ Relaxation strategies
- Support groups – creating community
- Respite

The Power of Pleasant Events & Support Groups

- Evidence-based tailored, dignified and purposive alternative to “you need to take care of yourself”
- Behavioral activation for mild depression
- Immediate practical consumer help
- Share difficult feelings – failure, regret
- Express disappointment in professionals, family, self and person with Alzheimer’s

Respite: What Do We Know?

- Most preferred, least available, and least affordable
- Timing, dosing, frequency, intensity, flexibility, and quality affect use and outcomes
- By the time respite is needed, there is a need for many other community supports

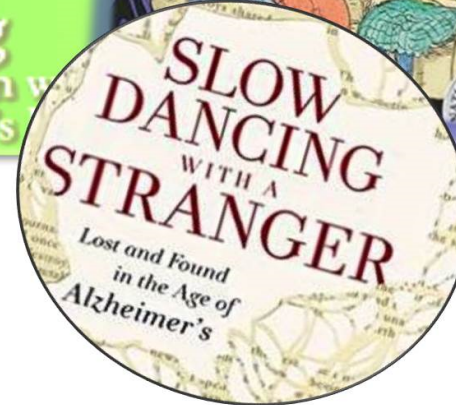
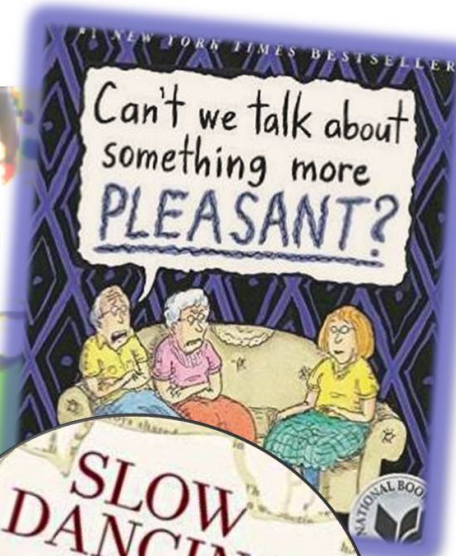
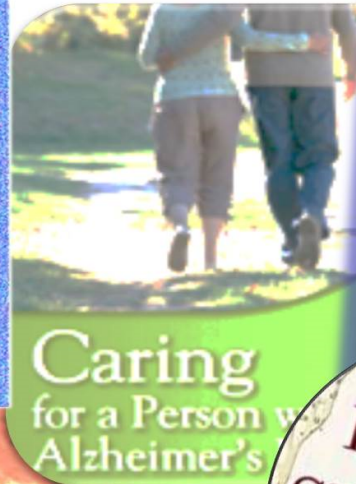
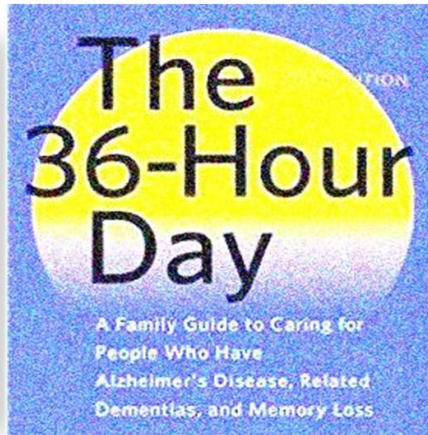
Duke Dementia Roundtable: Interprofessional Team Training

- Duke Geriatric Education Center: HRSA Alzheimer's Supplement (NAPA Workforce Enhancement Aim)
- Accessible PACE setting as site host
- Duke team (MD, MSN, SW, PA) led anchored facilitated interactive instruction over 2 yrs. of 8 monthly one-hour trainings after lunch networking time
- The Alzheimer's Project – video triggers free online
- 25 participants per session representing all disciplines and 25 community-based agencies from 3 counties

Summary: To Support Family Care

- Listen and assess before plan or recommend
- Make no assumptions – culture trumps
- Offer something to do and more than 1 option
- Don't underestimate the power of the telephone, email, and hard copy
- Prepare them: They will change their minds
- Offer previews: No commitments
- Quality services for individual “suffering” & “benefits”

DEMENTIA RESOURCES



Online Resources for Families

- http://www.alz.org/documents/mndak/taking_action_workbook.pdf
- <http://hartfordauto.thehartford.com/UI/Downloads/Crossroads.pdf>
- http://files.consumerfinance.gov/f/201310_cfpd_lay_fiduciary_guides_agents.pdf
- https://www.alz.org/national/documents/brochure_communication.pdf
- <https://www.nia.nih.gov/alzheimers/topics/caregiving>
- www.bathingwithoutabattle.unc.edu
- <http://nihseniorhealth.gov/>

The Dementia Cal MediConnect Project: A Case Example from California's Dual-Eligible Pilot Project

Debra L. Cherry, PhD



Funding

- This project was supported, in part by grant number 90 DC 2002-01-00, from the Administration on Aging, U.S. Administration for Community Living, DHHS, Washington, DC 20201 and the California Department of Aging.
- Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living or California Department of Aging policy.

Impact of Alzheimer's Disease in California

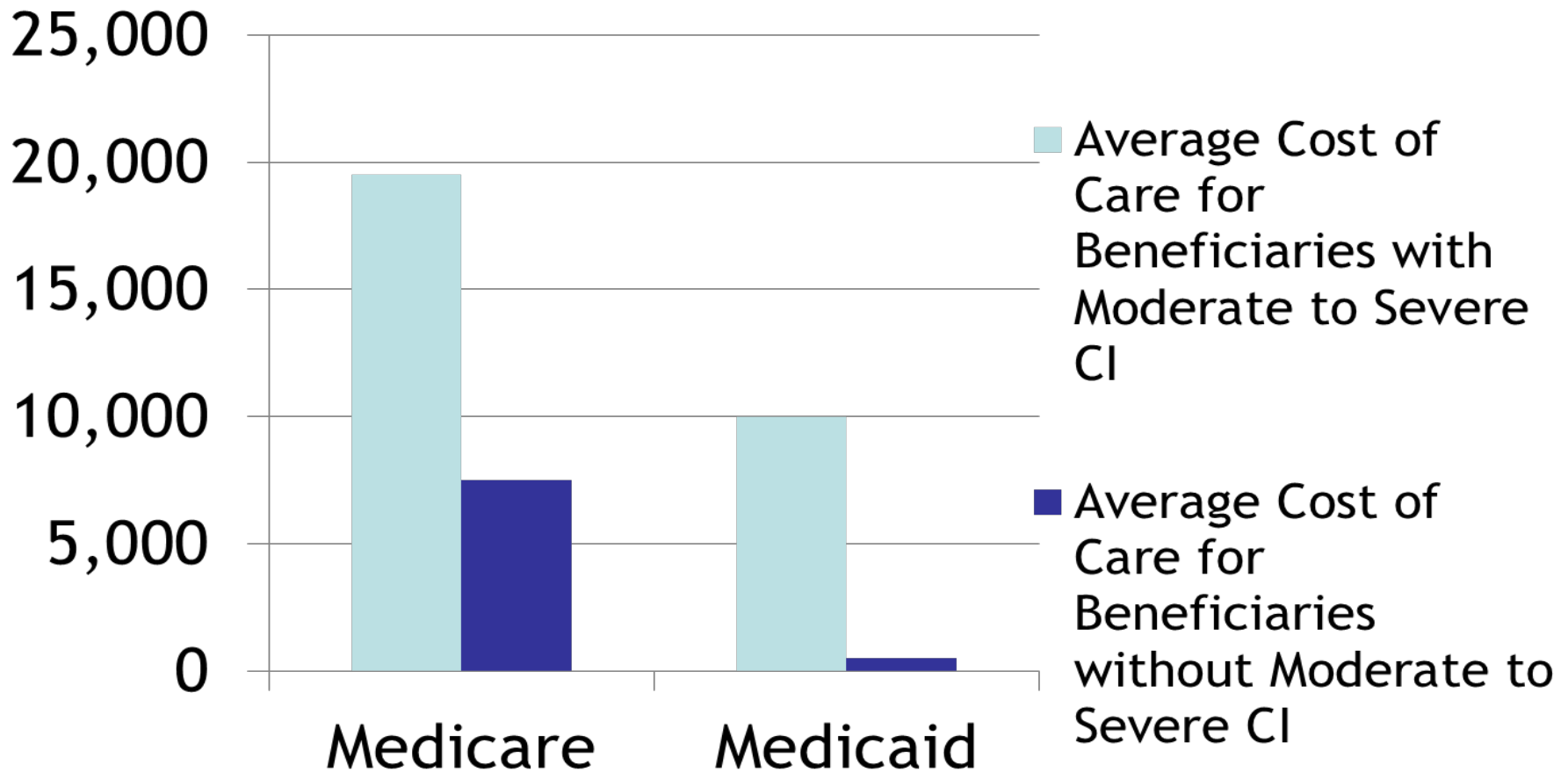
60,000-84,000
dual eligible seniors
in California have
ADRD

10% of
nation's
Alzheimer's
patients live
in California

Within the 8 counties
participating in the Pilot
Project, an estimated
20,000-28,000 dual eligible
beneficiaries have ADRD

Generation Alzheimer's (Alzheimer's Association, 2011)
AD Facts and Figures in CA (Alzheimer's Association, 2009)
Alzheimer's Association California Southland Chapter (2012)
Plassman, BL, et al. (2013). Amer Acad of Neurology. 1-6.
Slide courtesy of Cordula Dick-Muehlke, PhD

Cost of Care



Alzheimer's Association. 2015 Alzheimer's Disease Facts and Figures.

Bynum, J. (2011) Unpublished data from the Medicare Current Beneficiary Survey for 2008.

Dementia Cal MediConnect Project: Components

- Advocacy with health plans
- Care manager training and support
- Caregiver education and respite
- Support services through referrals to Alzheimer's Association (ALZ Direct Connect)
- Technical assistance to create systems change

Challenges to the Recognition of Dementia

- Some HRAs were not screening for cognitive impairment
- Difficulty making contact with members
- Families of the Duals may be less likely to bring dementia to the physician's attention
- Providers in diverse communities may share cultural views about dementia and help families to hide or deny the disease

Promote Better Detection of Patients with Dementia

- Review of HRA content
- Adoption of a validated screening tool
 - Example: AD 8 (ref.: Galvin JE et al (2005) Neurology)
- Train care managers and others to screen for dementia using this tool
- Develop a follow-up protocol if cognitive screen is positive

Monitor for Safety Issues

- Many families do not understand the disease
- Many families do not understand medication regimes
- Families are working and not at home to provide supervision
- Grandparents relied upon to care for children
- Grandchildren relied upon to care for person with dementia

Challenges to Family Caregiver Engagement (I)

Medical providers may not have institutionalized systems for identifying, documenting, and engaging the caregiver

- Poor management of co-morbid conditions
- Apparent non-compliance
- Medication mismanagement
- Behavior symptom mismanagement
- Unnecessary hospital readmissions, ER visits, and possibly even nursing home placement

Challenges to Family Caregiver Engagement (II)

Deciding who is “the caregiver”

- Caregiving may not be dyadic
- Decision-maker may not be apparent
- Family caregiver may not self-identify
 - Dementia seen as normal aging
 - Denial of need
 - Stigma

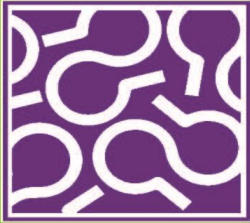
Recognize and Partner with Family/Informal Caregivers (I)

- Document who does what in the record so it can be shared
- Assess informal/family caregiver's needs
 - Caregiver Assessment Tool
 - Benjamin Rose Institute Caregiver Strain Index
(Ref: Bass, Noekler & Reschlin, 1996; Bass D, et al, 1994b)
- Assign patient & caregiver to a Dementia Care Manager
 - Standardized Care Plans (Derived from ACCESS and available at www.alz.org/socal)
(Ref: Vickrey B, et al. (2006) Annals of Internal Medicine)

Recognize and Partner with Family/ Informal Caregivers (II)

- Provide or refer informal/family caregiver for education
 - Plain Language Fact Sheets (English-Spanish)
(hallucinations, home safety, anger, getting lost, bathing, medications and more to come at www.alz.org/socal)

- Links to home and community-based services need to be suitable for lower income people
 - No cost or low cost legal and financial planning
 - Transportation to medical appointments



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- trip because of changes in balance or trouble walking
- have problems seeing clearly due to poor eyesight
- forget to turn off water, burners, ovens
- forget how to use knives, etc. or where to safely place burning objects

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California Southland Chapter

24/7 HELPLINE
(800) 272-3900
alz.org/socal

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KEEPING HOME SAFE

People with Alzheimer's or dementia may have trouble knowing what is dangerous or making safe decisions. By helping him or her feel more relaxed and less confused at home, you can help stop accidents.

WHAT CAN YOU DO?

Keep Things Simple

- make sure rooms are neat
- place "often used" items in the same place
- remove things that might break and aren't needed

Look at the Floor

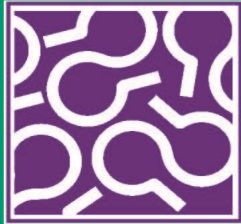
- remove small rugs, rugs that are thick, or rugs that might slide on floors
- don't shine or wax floors
- keep items off floors... cords, books, toys, bags, boxes, etc.
- make sure bathroom and kitchen floors are kept dry and avoid walking with wet feet
- use tables and chairs that are stable enough to lean on

Remove Dangerous Items

- keep all medicines... vitamins, aspirin, prescriptions... in a locked box, cabinet, or drawer
- place knives, scissors, guns, sharp tools, matches, and lighters out of sight or in a locked area
- move all cleaning supplies to a high shelf or lock them away
- take off knobs from the stove and oven

Don't Leave Him or Her Alone

- in the kitchen with the stove or oven on
- in the bathroom with water running
- anywhere with burning cigarettes, cigars, or pipes
- near an open or unlocked door or gate



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- forget to take their medications
- forget that they took their medication, so they take them again and again and again
- get sick or be poisoned because the wrong pills or too many pills were taken

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MEDICATIONS

People with Alzheimer's or dementia may need help with taking their medicine. Taking too much... or too little... or not following the directions... can be dangerous.

WHAT CAN YOU DO?

Watch Closely

- make sure he or she
 - takes the right number of pills at the right times
 - follows the directions on the medication
- do not leave medications in a pill box or cup on the counter
- do not leave him or her alone to take their medicine

Lock Away Medicine

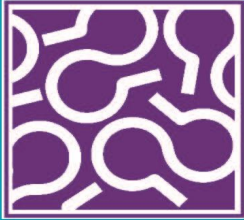
- make sure all medications are out of sight and out of reach

Talk to ALL the Doctors

- do not stop giving any medicine without asking the prescribing doctor first
- bring all medicines in a bag or box to every doctor
 - include vitamins, herbs, teas, creams, and other pills from the drugstore
- ask the doctor if medicines can be mixed into foods or drinks
 - this is helpful if you are having trouble getting your person to take their pills

NOTE: If you notice sudden changes like violent behaviors or trouble with bathroom accidents, call the doctor.

- these changes could be caused by a reaction to a medication or a new illness



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might be:

- afraid of falling
- feeling uneasy getting undressed in front of you
- scared or confused
- feeling helpless

BATHING

People with Alzheimer's disease or dementia may be afraid of bathing or uneasy with having someone help them with bathing. Sometimes they worry about falling or can have trouble knowing which is the hot versus the cold water faucets.

WHAT CAN YOU DO?

Prepare the Bathroom in Advance

- make sure the room is calm and warm
- run the water so it is not too hot or too cold
- don't use bright lights if possible

Make the Bathroom Safe

- use a non-slip mat in the tub or shower and as a bath mat
- consider a tub seat
- fill the tub with only 4 inches of water
- remove things that may be dangerous such as razors, nail clippers, hair dryer, etc.
- watch carefully – don't leave him or her alone

Allow Time & Be Positive

- allow your person to enjoy it... if he or she finds bath time relaxing
- stay calm
- be direct... "Your bath is ready now" instead of "Do you want to take a bath?"
- give one step directions... "Let's wash your left arm...good!, now your other one"
- be patient... don't rush

Be Realistic

- don't argue or get frustrated... a daily bath may be too much
- consider a sponge bath instead of a tub bath
- show what you need from them... pretend to wash your arm so that he or she can copy

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Caregiver Education

- Health plans are challenged to identify caregivers for disease education
- Easier sites for delivery of caregiver education
 - PACE
 - Adult Day Health Care Centers
 - Other MLTSS
- Consider
 - Training health plan health educators
 - Making referrals to CBOs for education
 - Plain language education is hard to find

Challenges to Partnerships with CBOs

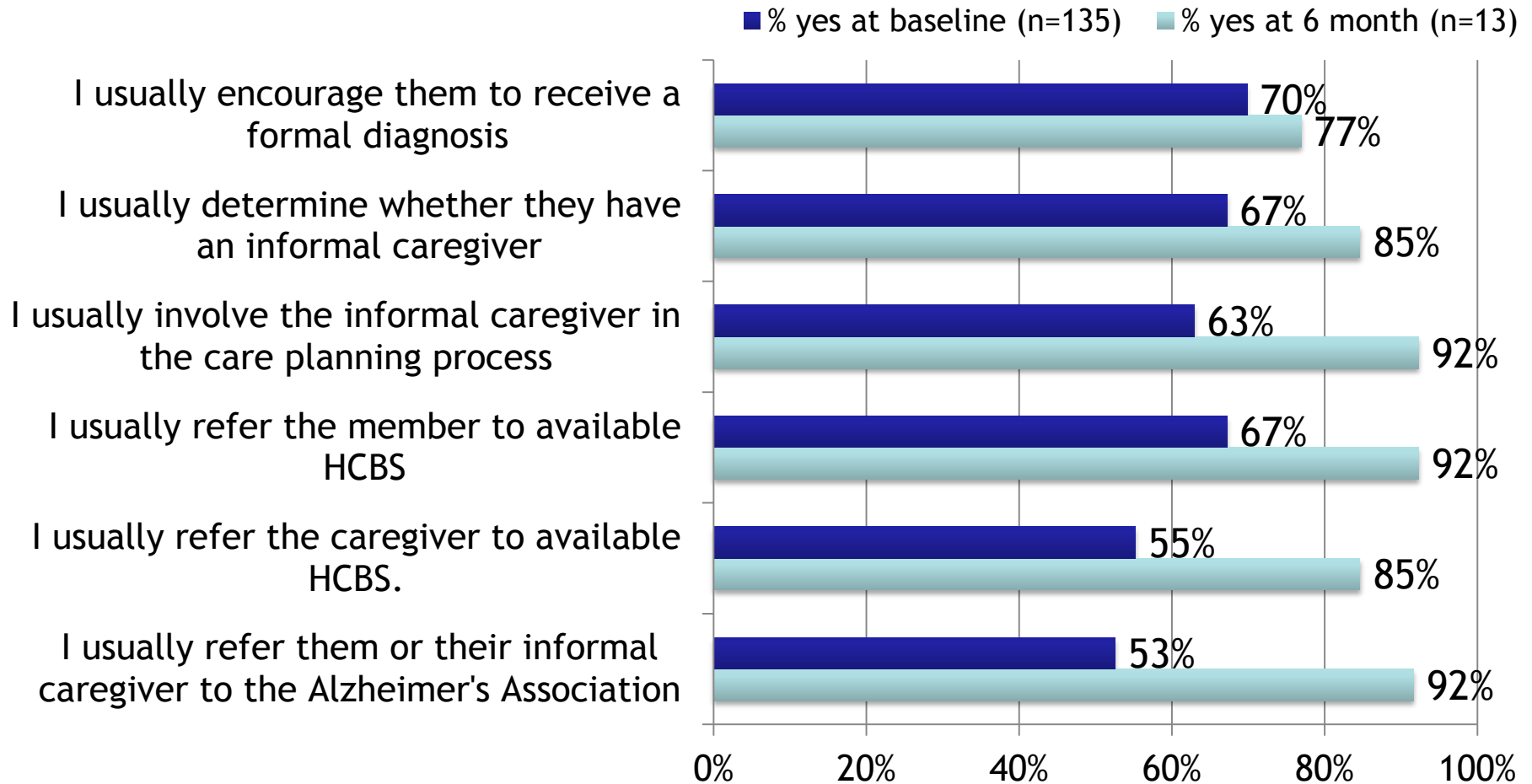
- Involves a culture change for both partners
 - MCOs expect timeliness and feedback
 - CBOs may not be HIPAA-compliant or have capacity for large quantities of referrals
- CBO services may require allocation of new resources
- Partners will need to invest time in order to better understand one another's cultures and services

Benefits of Partnerships with CBOs

- Wide array of supportive services
- Alzheimer's Association services
 - Support groups
 - Early stage programs
 - On-line and face-to-face education
 - Care consultants
 - 24/7 Helpline (800-272-3900)
 - MedicAlert®+Safe Return®
- Also consider partnerships with AAAs

Practice Change Reported by Care Managers

- When working with a member who may have ADRD...



Creating a Dementia Capable System of Care

- HRA/other assessments to include cognitive impairment and identification of caregivers
- Adoption of a validated screening tool
- Protocol for diagnosis if cognitive screen is positive
- Documentation of diagnosis in e-medical record
- Ability to identify family/informal caregiver(s)
- Adoption of caregiver assessment tools
- Adoption of standardized care plans
- Integration of caregiver education and support
- Partnerships with CBOs - Adoption of ALZ Direct Connect Fax Referral

Dementia Cal MediConnect Team

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▪ **For Project Materials Go To:**

www.alz.org/socal

▪ **Professional Training Tab**

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Questions



If you are applying for CME/CE credit the post-test is available at this time as well as the evaluation. You must complete the post-test by 2:00pm EDT.

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